Americans with Disabilities Act (ADA) - This statute, enacted in 1992, gives civil rights protections to individuals with disabilities that are like those provided to individuals on the basis of race, sex, national origin, and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, State and local government services and telecommunications.

Amphetamine-Dextroamphetamine - A medication made up of a combination of stimulants which is commonly used as part of a total treatment program to control Attention Deficit Hyperactivity Disorder (ADHD). Generic name for Adderall.

A Normalization and Development Instrument (A.N.D.I.) – A tool designed by the Department of Developmental Services to screen and evaluate the effectiveness and basic quality of day and residential programs according to normalization standards.

Anticonvulsants - Medications used to control seizures, which are defined as the physical results of abnormal electrical discharges in the brain and can include convulsions, sensory disturbances, or loss of consciousness. Some of these medications are also used to stabilize mood.

Antioxidant - Any substance that reduces oxidative damage. Such damage occurs when molecules in the body that do not have a balanced number of protons and electrons -- called free radicals--"steal" an electron from another molecule to achieve balance and stability in what becomes a damaging chain reaction. Antioxidants, such as Vitamins C and E, help by "donating" electrons to molecules that lack one in a non-damaging way that stops the chain-reaction.

Antipsychotic Medications - Psychiatric medications that are sometimes used in the treatment of autism spectrum disorders to help minimize irritability, aggression, and mood swings. There are two basic types of antipsychotic medications: atypical and conventional.

Applied Behavior Analysis (ABA) – Behavior analysis is a scientific approach to understanding behavior and how it is affected by the environment. "Behavior" refers to all kinds of actions and skills (not just misbehavior) and "environment" includes all sorts of physical and social events that might change or be changed by one's behavior. The science of behavior analysis focuses on principles (that is, general laws) about how behavior works, or how learning takes place. When a behavior is followed by something that is valued (a "reward"), that behavior is likely to be repeated. Through decades of research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may be harmful or that interfere with learning. Applied behavior analysis (ABA) is the use of those techniques and principles to address important problems, and to bring about meaningful behavior change. ABA is a common therapy for individuals with autism.

Architectural Barrier - A feature of a setting that prevents or impedes people with disabilities from using it. When these barriers are removed, the setting is said to be "barrier free" and implies full accessibility.

Area Boards - The Area Board is a Federally and State funded organization that provides, among other things, advocacy supports to families who have children receiving special education services and supports from school districts as well as those who

receive services from the regional center system. The 13 local area boards are an integral part of the State Council on Developmental Disabilities, assisting families and individuals with advocacy, training, coordination and implementation of a local Strategic Plan as well as the Council's State Plan.

Area Work Incentive Coordinator (AWIC) - Social Security Administration District Office Management Staff who provide information and services related to SSA's employment support programs. They also facilitate solutions to work incentive related problems with local SSA Offices.

Aromatherapy - A holistic treatment which involves caring for the body with pleasant smelling botanical oils.

Asperger's Syndrome - This is diagnosed in school-aged children who have social and behavioral symptoms of autism without the language delay. Measured intelligence is in the average to above average range. Frequently these children show an almost obsessive interest that is unusual in intensity and focus.

Aspie - Slang term for a person with Asperger's Syndrome (AS); sometimes used by people with AS to refer to themselves, but may be considered offensive when used by others.

Assessment - The process used to determine if a person is eligible for regional center services and to identify treatment needs.

Assistive Technology (AT) - Any item, piece of equipment, product, or system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of persons with disabilities.

Atomoxetine - Generic name for Strattera; a non-stimulant medication approved by the FDA for the treatment of Attention Deficit Hyperactivity Disorder (ADHD) in children, adolescents, and adults.

Attention-Deficit Disorder (ADD) - A frequently used term to refer to symptoms of attention-deficit/hyperactivity disorder involving a lesser or nonexistent component of hyperactivity.

Attention-Deficit/Hyperactivity Disorder (AD/HD) - The central feature of attention-deficit/hyperactivity disorder is a persistent pattern of inattention, hyperactivity, and/or impulsivity to a higher degree than is typical in individuals at a similar level of development. Some children diagnosed with an autism spectrum disorder also may be diagnosed with attention-deficit/hyperactivity disorder.

At-Risk: - Term used for children who have, or could have, developmental problems that may affect later ability to learn.

Auditory Integration Training (AIT) - A therapy based on a theory that the small internal organs of the ear can be exercised and that this can lead to modification of sound perception and behavior. Musical sounds are washed through a filtering apparatus that alters them, emphasizing some tones and reducing the intensity of others. The treatment is modified to suit individual needs as determined by special auditory testing. The

American Academy of Pediatrics and three other professional organizations consider it an experimental procedure.

Augmentative and Alternative Communication (AAC) - Non-speech methods of communication, including specialized gestures and sign language, charts, and electronic devices that can speak in response to keyboard entry.

Autie - Slang term for a person with autism. Sometimes used by people with autism to refer to themselves, but may be considered offensive when used by others.

Autism: Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

Autism Diagnostic Interview – Revised - Semi-structured interview for a clinician to use with a child's parent. It focuses on the three key areas defining autism: (1) reciprocal social interaction; (2) communication and language; and (3) repetitive, stereotyped behaviors.

Autism Diagnostic Observational Schedule – Generic - A semi-structured assessment of communication, social interaction, and play for individuals suspected of having autism or another pervasive developmental disorder (PDD). It involves direct observation of a person's behavior by an examiner who is taking careful note of traits and behaviors central to the diagnosis of autism.

Autism Screening Questionnaire - The former name for the autism screening instrument now known as the Social Communication Questionnaire.

Autism Spectrum Disorders (ASDs) – An umbrella term used to refer to a group of similar developmental disabilities, including Autistic Disorder, Asperger's Syndrome (AS), Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder (CDD), and Rett's Disorder, as defined by the psychiatric manual, DSM-IV (*Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*). The hallmark of all of these conditions is a marked impairment in social interaction and language/communication skills, as well as the presence of restricted, repetitive behaviors and interests.

Autoimmune - Any process or disorder in which the immune system, in addition to attacking viruses or other harmful intruders, attacks healthy body tissues. Some scientists believe autoimmune processes may be involved in autism.

Autosomal Dominance - A pattern of inheritance characteristic of some genetic diseases. "Autosomal" means that the gene in question is located on one of the numbered, or non-sex, chromosomes. "Dominant" means that a single copy of the disease-associated mutation is enough to cause the disease. This is in contrast to a recessive disorder, where two copies of the mutation are needed to cause the disease. Huntington's disease is a common example of an autosomal dominant genetic disorder.

Aversive Treatment - In psychology, aversives are unpleasant stimuli that induce changes in behavior through punishment; by applying an aversive immediately following a behavior, the likelihood of the behavior occurring in the future is reduced. A potentially harmful procedure used in an attempt to reduce certain negative behaviors. Aversives can vary from being slightly unpleasant or irritating (such as a disliked color) to physically damaging (such as an electric shock).

Behavior Intervention – Acceptable interventions include positive behavioral support strategies that do not cause pain or trauma, and that which respect the person's individual needs and dignity.

Behavior Modification - A way to help people acquire behaviors by structuring the person's environment to reinforce or reward positive behaviors.

Behavior Management Program - A time-limited day program that serves adults with a severe behavior disorder and or dual diagnosis (mental retardation and mental illness) who, because of their behavior problems are not eligible for, or acceptable in any other day program.

Behavioral Summarized Evaluation (BSE) – A rating scale which was designed to measure behavior changes in autistic children and adolescents. The BSE is usually completed by someone having daily contact with the child, such as a parent or teacher. It has often been used as a measure of a child's behavior over time, especially in the context of intervention studies.

Benadryl - Brand name for diphenhydramine; a medication that blocks histamine, a substance the body makes during an allergic reaction. Also sometimes used to treat dystonic reactions, (i. e. prolonged contractions of muscles that may result from the use of conventional antipsychotic medications.)

Bipolar Disorder - In this psychiatric disorder, formerly called manic depression, periods of sadness and low energy alternate with periods of elevated, silly, or irritable mood, sometimes combined with inflated self-esteem, a decreased need for sleep, racing thoughts, or out-of-control risk-taking behavior. Some children diagnosed with an autism spectrum disorder also may be diagnosed with bipolar disorder.

Board and Care - Residential facilities licensed by the State Department of Social Services, Community Care Licensing Division. These licensing categories include three types of facilities: 1) ADULT RESIDENTIAL FACILITY: serves adults with developmental or mentally disabled, ages 18-59 years; 2) GROUP HOME: serves individuals birth through 17 years old with a structured environment with services provided by staff employed by the licensee; 3) SMALL FAMILY HOME: serves persons with developmental disabilities, mental disorders or physical handicaps aged birth through 17 years old with care provided in the licensee's family residence.

Braided Funding – Weaving together of more than one fund source to support needed services.

Broad Autism Phenotype - Abbreviated BAP, this refers to the finding that relatives of people with autism often have mild autism-like characteristics including difficulty reading social cues, social anxiety, or obsessive-compulsive traits. The fact that autism-like

features appear in members of the same family supports the notion that there is a genetic basis for autism.

Brushing Technique - A form of Sensory Integration Therapy in which firmly stroking a soft surgical brush on the back, arms, and legs is used to reduce over- or under-sensitivity to touch.

California Children's Services (CCS) – A statewide program that assists children under the age of 21 who have a serious medical condition and require specialty medical care.

California Master Plan - A plan to help provide services for students with disabilities in the California School System. It describes who is disabled and what types of services are available and how they will be offered.

Carbamazapine - A drug used to prevent and control seizures; may also be used to treat certain mental/mood conditions (e.g. Bipolar Disorder, Schizophrenia) and certain types of nerve pain. Generic name for Tegretol.

Care Provider - A health care provider is an individual or an institution that provides preventive, curative, promotional or rehabilitative health care services in a systematic way to individuals, families or communities. Also, an operator of a licensed community care facility. (CCF)

C.A.R.F. - An international, non-profit organization to provide accreditation standards and surveyors for organizations working in the human services field worldwide. Among the many areas of practice represented in the CARF standards are aging services; behavioral health, which includes psychosocial rehabilitation and assertive community treatment; child and youth services; employment and community services; medical rehabilitation; and opioid treatment programs. Also, a survey conducted by the Commission on the Accreditation of Rehabilitation Facilities, designed to evaluate the effectiveness of various types of employment programs and pre-employment programs and services.

Cartooning - A technique in which cartoon sketches are used to enhance social understanding by making thoughts, perspectives, and verbalizations visible. For example, two characters in a social situation will appear along with "bubbles" which contain what each character was saying, thinking, or feeling.

Casein-Free Diet - A special diet that limits intake of casein, a protein found in milk and products containing milk.

Catapres - A medication used primarily to treat high blood pressure, but which may also be used to treat migraine headaches and Attention Deficit Hyperactivity Disorder (ADHD). Brand name for clonidine.

Celiac Disease - An inherited autoimmune disorder that usually affects several organs in the body before diagnosis and treatment. When a person with celiac disease consumes any food, beverage, or medication containing wheat, barley, rye, and sometimes oats, their immune system is "triggered" and responds by damaging the lining of the intestinal tract.

Cerebral Palsy (CP) – A condition that is characterized by problems with muscle control and coordination as a result of trauma to parts of the brain at birth or during early life.

Chelation - The process of removing a heavy metal such as lead or mercury from the body via the bloodstream using a medication that binds to the metal, allowing the body to excrete it through urine or stool. See also clathration.

Childhood Autism Rating Scale – A test which aids in evaluating a child's body movements, adaptation to change, listening response, verbal communication, and relationship to people. The child's behavior is rated on a scale based on deviation from the typical behavior of children of the same age.

Childhood Disintegrative Disorder (CDD) - A rare condition occurring in 3 to 4 year olds who, having developed normally until age 2, experience a marked deterioration in intellectual, social, and language functioning. Children with CDD come to resemble children with autism, but only after a relatively prolonged period of normal development.

Chlorpromazine - The generic name for Thorazine; one of the conventional antipsychotic medications, which were developed in the 1950s, '60s, and '70s and commonly caused extrapyramidal side effects.

Citizen Advocacy - A program designed to foster a close voluntary friendship between a person whose rights may be in danger and another who is informed about the person's rights and is willing to advocate for them.

Clathration - The process of removing a heavy metal from the body by giving a substance orally which then binds with the heavy metals until they are eliminated from the body. See also chelation.

Client Developmental Evaluation Report (CDER) - A diagnostic and evaluation instrument used by regional centers. All regional center clients are evaluated with C.D.E.R.

Client Program Coordinator (CPC) (Also called Case Manager) - A person responsible for the overall planning, coordination and implementation of an Individual Program Plan. Regional Centers employ Client Program Coordinators.

Client Rights Advocate - A specific staff member designated to assist individuals with special developmental needs to exercise all rights guaranteed by law.

Clonidine - A medication used primarily to treat high blood pressure, but which may also be used to treat migraine headaches and Attention Deficit Hyperactivity Disorder (ADHD). Generic name for Catapres.

Clozapine – The generic name for Clozaril; an atypical antipsychotic medication used to treat psychiatric disorders, such as schizophrenia. This medication helps restore the balance of neurotransmitters in the brain. When used in the treatment of autism spectrum disorder, clozapine can ease nervousness.

Clozaril – The brand name for clozapine; an atypical antipsychotic medication used to treat psychiatric disorders, such as schizophrenia. This medication helps restore the

balance of neurotransmitters in the brain. Also, has been prescribed to reduce anxiety in the treatment of autism spectrum disorders.

Cognitive Behavioral Therapy (CBT) – The term that refers to psychotherapeutic method which attempts to decrease or eliminate problem behaviors and painful emotions by modifying the distorted attitudes, thoughts, and beliefs that trigger them. The concept of CBT is that a change in the interpretation of a situation or relationship, will also change the emotions, feelings, and/or perceptions that are associated with that situation or relationship.

Cognitive Disability – Also called "intellectual disability", cognitive disability is a preferred term to describe the condition formerly referred to as mental retardation.

Comic Strip Conversations - A social skills training tool that involves "drawing" conversations to help children with ASD learn the social rules that others learn more naturally.

Community Advisory Committee (CAC) – A group of individuals who are appointed to advise the SELPA on various aspects of the Local Plan.

Communicatively Disabled (CD) – This term refers to individuals who are deaf, hard of hearing, aphasic, severely language impaired, or have other speech and/or communication disorders.

Community-Based Day Programs - Programs which are located in the community rather than at a State Developmental Center (DC) and which provide service to regional center clients on an hourly or daily, but less than 24 hour basis. The following programs are examples of community-based day programs: Activity Center, Adult Development Centers, Behavior Management Programs, Independent Living Programs, Infant Early Intervention Programs and Social Recreation Programs.

Community Based Program (provider definition) - A program where the vast majority of classes and activities for participants occur in the participant's local natural environment and not in a segregated setting.

Community Care Facility (CCF) - Facilities (majority with six beds or less) that provide residential services (room and board) along with varying degrees of supervision.

Community Care Licensing (CCL) – The division of California's Department of Social Services that is responsible for licensing a broad range of facilities, including group homes for adults with developmental disabilities. CCL is also responsible for investigating and taking action on complaints about the facilities it licenses.

Community Integration - Presence, participation and interaction in natural environments.

Community Colleges (C.C.S) - Two-year higher education schools that serve students both with and without disabilities and which currently provide prevocational, vocational and academic training for persons with disabilities.

Community Placement Plan (CPP) - A yearly plan developed by each regional center for placement of persons out of state developmental centers.

Community Supported Living Arrangement (CSLA) - Community Supported Living Arrangements (CSLA) provide individuals with the support necessary to enable them to live in their own homes, apartments, family homes, or rental units with: No more than two other non-related recipients of these services; or Members of the same family regardless of the family size. Community Supported Living Arrangements provide full range of community based support, including friends and neighbors, for the delivery of supervision and other necessary interventions.

Community Work Incentive Coordinator (CWIC) - Social Security Administration trained staff with specialized knowledge of disability benefits and work incentives. They provide individualized benefits counseling and on-going benefits management

Comorbid - Two or more diseases or disorders which, although separate and unique, are occurring at the same time in the same person. For example, ADHD and autism are often comorbid conditions.

Conservatorship - A legal process by which an individual is appointed by the court to care for the personal welfare and/or financial welfare of an adult who is unable to adequately care for himself/herself or manage his/her behavior.

Consumer - A person (Primary Consumer) or relative of a person (Secondary Consumer) who uses developmental services.

Copy Number Variation (CNVs) - A form of structural variation (abnormal changes) in the human chromosomes (genome) that results in the cell having an abnormal number of copies of one or more sections of the DNA. CNVs correspond to relatively large regions of the genome that have been deleted (fewer than the normal number) or duplicated (more than the normal number) on certain chromosomes. This variation accounts for roughly 12% of human genomic DNA. CNVs may be either inherited or occur as new (spontaneous) mutations.

Cortisol - Produced by the adrenal glands, cortisol is a key hormone involved in regulating the human body's stress response. Recent studies of stress exposure shortly before or during pregnancy, resulting in higher cortisol levels crossing into the placenta, have failed to show a link between this hormone and the later probability that the child will be diagnosed with ASD.

County Council - Local boards empowered by county boards of supervisors and given the responsibilities to plan, advocate and monitor services to persons with developmental disabilities within a county. These councils are very active in some parts of California; in others, they are non-existent.

Dairy-Free Diet - A special diet that eliminates milk and any products containing milk.

Day Nursery: - A nonresidential facility for children to aid them in developing pre-academic skills. Such a facility is also known as a preschool nursery or school.

Day Training and Activity Center (DTAC) - Focuses on people whose needs include both prevocational and pre-independent living skills. In practice, these programs are often segregated, but need not be.

Day Service Provider - A person or persons who provide training and education for persons with developmental disabilities. This may be in a day training and activity center, community college, sheltered employment, etc.

De Novo Mutation - A genetic difference that is not inherited but arises spontaneously due to a gene alteration that appears in one family member as a result of a mutation in an egg or a sperm of one of the parents, or in the fertilized egg itself. The mutation is not part of the parent's overall genetic code. See also copy number variation and mutation.

Deinstitutionalization - A practice or goal of reducing the number of people living in congregated and segregated institutional settings. When implemented appropriately, this practice is based on the concepts of normalization and least restrictive environment.

Depakene - An anti-epileptic, anti-convulsant medication. Brand name for valproate (valproic acid).

Depakote - A medication used to treat seizure disorders, certain psychiatric conditions, and to prevent migraine headaches. Brand name for divalproex sodium.

Department of Developmental Services (DDS) - The agency through which the State of California provides services and supports to individuals with developmental disabilities. These disabilities include mental retardation, cerebral palsy, epilepsy, autism and related conditions. Services are provided through state-operated developmental centers and community facilities, and contracts with 21 nonprofit regional centers. The regional centers serve as a local resource to help find and access the services and supports available to individuals with developmental disabilities and their families. In addition, the Department sets policy, determines rates, and advocates for people through its various departmental divisions. They are also the lead agency for Early Start through IDEA-Part C.

Department of Education (also California Department of Education or CDE) - This is the California agency that oversees public education. The department oversees funding and testing, and holds local educational agencies accountable for student achievement. Its stated mission is to provide leadership, assistance, oversight, and resources (via teaching and teaching material) so that every Californian has access to a good education. The State Board of Education is the governing and policy-making body, and the State Superintendent of Public Instruction is the nonpartisan elected executive officer. Superintendents serve four-year terms. The Superintendent serves as the state's chief spokesperson for public schools, and provides education policy and direction to local school districts. He also serves as an ex officio member of governing boards of the state's higher education system.

Department of Health Services (DOH) – The state agency that provides a number of health services to all people. Also operates California Children's Service, a therapy and medical treatment program for children with physical disabilities and health problems through age 21.

Department of Rehabilitation (DOR or DR) – The state agency whose mandate is to assist residents of California with disabilities to become gainfully employed. They serve a broad spectrum of persons with disabilities. They are responsible for all initial supported employment services such as assessment, job placement and initial job coaching through stabilization. Funding is generally for time limited intensive services.

Department of Social Services (DSS) - The state agency that provides licenses and monitors community care facilities such as residential and day services. Also funds In-Home-Support-Services (IHSS) for people who live at home but may need help in self-care.

Developmental - Pertaining to successive changes during the process of natural growth.

Developmental Center - Synonymous with state hospital.

Developmental Delay - A delay in one or more of the four developmental areas: cognitive, physical, psychosocial or self-help skills.

Developmental Disability (DD) - California defines a person with a developmental disability as anyone who has acquired mental retardation, autism, pervasive developmental disorder not otherwise specified, epilepsy or cerebral palsy before age 18 and is likely to need special services throughout life. The Federal definition uses age 22 and looks at a person's range of abilities instead of diagnostic categories.

Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition - Published by the American Psychiatric Association; a comprehensive listing of mental health disorders and the criteria for diagnosing them. This book is considered the "bible" for mental health professionals making psychiatric diagnoses in the United States as well as in many other countries. The diagnostic categories in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition,* are also used by insurance companies to determine coverage and reimbursement for mental health issues.

Disability: - A physical or mental condition, which limits, or will limit if not corrected, a person's functioning.

Divalproex Sodium - A medication used to treat seizure disorders, certain psychiatric conditions, and to prevent migraine headaches. Generic name for Depakote.

Down Syndrome: - A condition associated with a chromosome abnormality, usually trisomy (addition of a third chromosome to a pair) of chromosome 21, resulting in moderate to severe mental retardation, and frequently accompanied by physical anomalies.

Dual Diagnosis: - In terms of developmental disabilities, an individual who is both developmentally disabled and mentally ill.

Dyslexia: - a very broad term defining a learning disability that impairs a person's fluency or comprehension accuracy in being able to read, and can manifest itself as a difficulty with phonological awareness, phonological decoding, orthographic coding, auditory short-term memory, or rapid naming. Dyslexia is separate and distinct from reading difficulties resulting from other causes, such as a non-neurological deficiency with vision or hearing,

or from poor or inadequate reading instruction. It is believed that dyslexia can affect between 5 to 10 percent of the population.

Dystonic Reactions - Prolonged contractions of muscles, including any muscles such as those in the neck or arms, or even the muscles around the eye (in which case the individual seems to have a fixed gaze upward); among the extrapyramidal side effects sometimes resulting from use of conventional antipsychotic medications.

Ear Hitting - The act of hitting one's ears with one's hands; one of the repetitive and possibly self-stimulating behaviors associated with individuals having an autism spectrum disorder. Ear hitting may sometimes be the result of a person hitting their ears to block out sounds to which they are so sensitive, the sounds are experienced as painful.

Early Intervention: - Early intervention is a system of coordinated services that promotes the child's growth and development and supports families during the critical early years. Early intervention services to eligible children and families are federally mandated through the Individuals with Disabilities Education Act. These services often involved medical, educational, and psychosocial professionals. Infant intervention programs also provide emotional support, guidance and information to parents. The Education of the Handicapped Act Amendments of 1986, Part H of Public Law (P.L.) 99-457, provides for discretionary funds to assist states in establishing statewide, comprehensive systems of early intervention services for infants and toddlers with developmental delays who are at risk, and their families. It was reauthorized as IDEA Part C in 2004. The California Department of Developmental Services is designed as the lead agency for this program.

Echolalia - The immediate and involuntary repetition (echoing) of words or phrases just spoken by others. Echolalia is often cited as a symptom of autism.

Education for All Handicapped Children Act of 1975 (Public Law 94-142 or I.D.E.A.) The Individuals with Disabilities Education Act is a federal law which mandates the following for students with disabilities: A free and appropriate public education in the least restrictive environment; priorities for service; procedural safeguards; definitions of disabilities; and the Individualized Education Plan Program (I.E.P.).

Electroencephalogram - The study of electrical current within the brain. Electrodes are attached to the scalp and wires attach these electrodes to a machine which records the electrical impulses. Results are either printed out or displayed on a computer screen.

Eligibility – In the context of individuals with developmental disabilities, the determination about whether a person meets the requirements set by the State of California to have services and supports paid for by the regional center. There are different eligibility requirements for Lanterman Act services and Early Start services and Prevention services through Regional Centers.

Emotional Disturbance (ED) – Persons who exhibit one or more characteristics of a severe emotional disturbance specified by law and whose condition has existed for a long period of time and to a marked degree.

Employment Development Department (EDD) – The state agency that provides job referral services, benefits, and some training for persons who are looking for work.

Encopresis - Involuntary defecation, especially if not due to a physical defect or illness; sometimes associated with a neurological disorder, especially in children if they are past the age where bowel control is usually achieved.

Enuresis - Lack of control of urination, especially during sleep; bedwetting. Sometimes associated with a neurological disorder, especially in children if they have reached the age past which toilet training is usually achieved.

Assessment, Environmental - An evaluation of the physical setting in which a child lives or learns (e.g. home or classroom) intended to identify ways to improve a child's functioning or behavior. For example, an environmental assessment of a classroom might reveal that noise level or flickering lights are contributing to the meltdowns of a child with an autism spectrum disorder; adjustments can then be made to improve the learning environment.

Environmental Stressor - An external factor a person encounters, such as a pesticide, virus, or medication. A person with a genetic vulnerability has one or more genes which may turn "on" or "off" or otherwise be changed due to the action of an environmental stressor. This interaction may be associated with some ASD characteristics.

Epidemiology - The study of the distribution of diseases in populations and of factors that influence the occurrence of disease. To say there is an interest in the epidemiology of autism is to say scientists are trying to find out how many people have it, where they are located, and what genetic, geographic, and environmental factors they share.

Epilepsy – A medical condition that produces seizures affecting a variety of mental and physical functions. A seizure happens when a brief, strong surge of electrical activity affects part or all of the brain. One in 10 adults will have a seizure sometime during their life. Seizures can last from a few seconds to a few minutes. They can have many symptoms, from convulsions and loss of consciousness to some that are not always recognized as seizures by the person experiencing them or by health care professionals: blank staring, lip smacking, or jerking movements of arms and legs.

Essential Fatty Acids - Necessary fats that humans need for growth and development. These cannot be made by the body, and must be obtained in the diet. Examples include Omega 3 Fatty Acids and Omega 6 Fatty Acids.

Etiology - The cause or origin of a disease or disabling condition.

Evidence-Based Practice (EPB)- This entails making decisions about how to promote health or provide care by integrating the best available evidence with practitioner expertise and other resources, and with the characteristics, state, needs, values and preferences of those who will be affected. This is done in a manner that is compatible with the environmental and organizational context. Evidence is comprised of research findings derived from the systematic collection of data through observation and experiment and the formulation of questions and testing of hypotheses. The gold standard for an "evidence-based" therapeutic intervention is often considered to be the randomized, double-blind, placebo-controlled trial.

Executive Function - The ability to coordinate and apply one's own mental capacity. It is what permits us to initiate goal-directed action, decide not to take inappropriate action,

screen out unwanted sensory stimuli, think abstractly, and choose alternate action as roadblocks arise. It is not intelligence, per se, but Mission Control. Many people with ASD appear to have impaired executive function, especially in regards to planning, organization, and mental flexibility.

Expressive Language - A person's ability to use language to make evident their thoughts, wants, and needs.

Externalizing Symptoms - This term refers to symptoms involving acting-out behaviors such as aggression or impulsivity.

Extrapyramidal Side Effects – A term that refers to the side effects, including rigidity, persistent muscle spasms, tremors, and restlessness, frequently associated with the use of conventional antipsychotic medication. The more recently developed atypical antipsychotics rarely produce these side effects.

Eye Gaze - A form of nonverbal communication. Very young children, even before they can talk, begin to initiate social interaction with their parents and others around them. Eventually, children will share their interest in something by pointing at it and alternating their gaze from their parent to the object and then back again, one of the behaviors of joint attention. Infants on the autism spectrum lack the overriding interest typically developing infants show for human faces and tend not to engage in this important social behavior.

Facilitated Communication - A method by which a facilitator supports the hand or arm of a communicatively impaired individual while using a keyboard or other devices with the aim of helping the individual to develop pointing skills and to communicate. The procedure is controversial, since most peer reviewed scientific studies conclude that the typed language output attributed to the clients is directed or systematically determined by the therapists who provide facilitated assistance.

Facilitation Services - Services whereby an individual aids a member of a policy-making board to perform the essential functions of his/her position.

Fair Hearing - A procedure used by people who wish to question the decision of an agency regarding the type or amount of service they receive.

Fetal Testosterone - Prenatally produced testosterone, a male hormone associated with development of physical and cognitive gender characteristics. One theory holds that high levels of fetal testosterone may contribute to later development of autistic characteristics in children (though not necessarily the development of a diagnosed autism spectrum disorder).

Fine Motor Skills - Skills, usually mastered in early childhood, that involve your ability to effectively use small muscles to carry out precise motor movements. Examples include actions like picking up a cracker or writing with a pencil.

Finger Flapping - The act of moving one's fingers sharply up and down or back and forth; one of the repetitive and possibly self-stimulating behaviors associated with individuals having an autism spectrum disorder.

First-Generation Antipsychotics - Antipsychotic medications, such as Thorazine, that were developed in the 1950s, '60s, and '70s. They commonly caused extrapyramidal side effects, which are much less characteristic of the atypical antipsychotics in wide use since the '90s.

Floortime Therapy - This is a specific therapeutic technique based on the Developmental Individual Difference Relationship Model (DIR) developed in the 1980s by Dr. Stanley Greenspan. The premise of Floortime is that an adult can help a child expand his circles of communication by meeting him at his developmental level and building on his strengths. Therapy is often incorporated into play activities -- on the floor. The goal of Floortime is to help the child reach the following six developmental milestones: Self-regulation and interest in the world; intimacy; two-way communication; complex communication; emotional ideas; emotional thinking.

Fragile X Syndrome - A genetic disorder caused by a defective gene on the X-chromosome. Fragile X, which affects as many as one in 2000 males and one in 4000 females, is one of the most common causes of inherited mental impairment and the most common known cause of autism and autism-like conditions. Characteristic features of Fragile X Syndrome in boys include a long face, prominent or long ears, delayed speech and language development, large testes, hyperactivity, tactile defensiveness, gross motor delays, and autistic-like behaviors. Girls are much more mildly affected.

Free Appropriate Public Education (FAPE) - Each public school system is responsible for ensuring that each child with disabilities is served appropriately, at no expense to the parent.

Functional/Critical Skills - Those skills that enable an individual to communicate, interact with others and to perform tasks that have practical utility and meaning at home, in the community, or on the job.

Functional Assessment - The process of determining the relationship between events in a person's environment and the occurrence of challenging behaviors. This process involves: identifying and defining the challenging behavior; identifying the events and circumstances regularly associated with the occurrence and the nonoccurrence of the challenging behavior; determining the social function or the purpose of the challenging behavior.

Functional Communication Training (FCT) - FCT involves replacing challenging behavior with more desirable behavior that will achieve the same goals for the child. For example, a parent might teach a child who has a meltdown whenever he becomes overly hungry to use his words to request a snack.

Generalized Anxiety Disorder - Individuals with generalized anxiety disorder experience excessive anxiety and worry for more days than not for at least six months. This anxiety, which concerns a number of events or activities and does not result from other disorders, such as panic disorder, may be accompanied by restlessness, fatigue, lack of concentration, irritability, and other symptoms. Some children diagnosed with an autism spectrum disorder, as well as members of their family, also experience anxiety symptoms or may be diagnosed with anxiety disorders.

Generic Services - Services available to all persons residing within a given area (e.g., city, county, or state) without additional qualifications or requirements, such a public education, mental health services, and parks and recreation programs.

Goals - Broad or general statements which describe what needs to be learned by the consumer/student.

Genes - A gene is a unit of heredity in a living organism. It normally resides on a stretch of DNA that codes for a type of protein or for an RNA chain that has a function in the organism. All living things depend on genes, as they specify all proteins and functional RNA chains. Genes hold the information to build and maintain an organism's cells and pass genetic traits to offspring, although some organelles (e.g. mitochondria) are self-replicating and are not coded for by the organism's DNA. Genes, which are made up of DNA, carry the instructions for hereditary traits in organisms. Humans have about 30,000 genes on their chromosomes; usually each person has two copies of each gene, one inherited from each parent. See copy number variation for an exception.

Genetic Vulnerability - An underlying inherited susceptibility. In the case of ASD, a predisposition to autistic behaviors may be common in the general population, but this predisposition may not be apparent in an individual unless it is "triggered," or influenced, by environmental factors.

Genotype - The genetic makeup, as distinguished from the physical appearance (phenotype), of an organism or a group of organisms; the DNA material that was passed to the organism by its parents at the organism's conception.

Geodon - Brand name for ziprasidone; an atypical antipsychotic medication used to treat psychiatric disorders, such as schizophrenia, and symptoms associated with bipolar disorder. This medication helps restore the balance of neurotransmitters in the brain. When used in the treatment of autism spectrum disorder, Geodon can ease nervousness and help improve concentration.

Gluten-Free Diet - A diet that involves the avoidance of gluten, a protein contained in wheat, barley, and rye, and a similar protein in oats.

Gross Motor Skills - Skills, usually mastered in early childhood, that involve the ability to effectively use large muscles. Examples include: lifting your head, sitting up, and riding a bike.

Guardianship - A judicial process whereby the legal decision-making power from one individual is transferred to another who has been appointed to serve, assist, and protect the person by helping the individual make decisions or by making the decisions for him/her. This applies to persons under the age of 18 years.

Habilitation – The assistance that is provided to an individual with achieving developmental skills when impairments have caused delaying or blocking of initial acquisition of the skills. Habilitation can include cognitive, social, fine motor, gross motor, or other skills that contribute to mobility, communication, and performance of activities of daily living and enhance quality of life. The purpose is to prepare and maintain consumers at their highest level of vocational functioning and/or prepare them for referral

to vocational rehabilitation services. Habilitation services were provided by the Department of Rehabilitation until July 1, 2004 when they were transferred to the Department of Developmental Services.

Haldol – The brand name for haloperidol; one of the conventional antipsychotic medications, which were developed in the 1950s, '60s, and '70s and commonly caused extrapyramidal side effects.

Haloperidol – The generic name for Haldol; one of the conventional antipsychotic medications, which were developed in the 1950s, '60s, and '70s and commonly caused extrapyramidal side effects.

Hand Flapping - Wagging one's hands sharply up and down from the wrist; one of the repetitive and possibly self-stimulating behaviors associated with individuals having an autism spectrum or other mental disorder.

Head Banging - Banging one's head against a surface; one of the repetitive and possibly self-stimulating behaviors associated with individuals having an autism spectrum or other mental disorder. It has been theorized that in some cases this behavior could be related to hypersensitivity to certain stimuli in the environment. For example, if a sound bothers an individual, he/she may react by hitting his/her head or ears.

Health and Welfare Agency - The state agency which coordinates the work of the Department of Developmental Services, Department of Rehabilitation, Employment Development Department, Department of Social Services, Department of Health Services and the Department of Mental Health.

High-Functioning Autism (HFA) - An informal term applied to autistic people who are deemed to be "higher functioning" than other autistic people, by one or more metrics.[1] There is no consensus as to the definition.[1] HFA is not yet a recognized diagnosis in the DSM-IV-TR or the ICD-10.

The amount of overlap between HFA and Asperger syndrome is disputed. Some researchers argue that the two are distinct diagnostic entities, others argue that they are indistinguishable.

Holding Therapy - A therapy in which parents hold a child even if the child is resisting. The parent also tries to establish eye-contact.

Hyperlexia - A trait in which a child reads single words very early. Often, hyperlexic children will have a precocious ability to read but will learn to speak only by rote and heavy repetition, and may also have difficulty learning the rules of language from examples or from trial and error, which may result in social problems. Their language may develop using echolalia, often repeating words and sentences. Often, the child has a large vocabulary and can identify many objects and pictures, but cannot put their language skills to good use. The social skills of a child with hyperlexia often lag tremendously. Hyperlexic children often have far less interest in playing with other children than do their peers.

Hypersensitive - Extremely sensitive to various stimuli, such as touch, sound, or light. Many individuals with an autism spectrum disorder are hypersensitive, finding many stimuli that are common in the everyday world so intense as to be painful. For example, what most people would perceive as an acceptable level of noise in a classroom or a grocery store may be experienced as deafening and distressing.

Hypersomnia - Characterized by sleeping much more than usual during the daytime; one of the symptoms of clinical depression as defined by the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV).*

Hyposensitive - Being far less sensitive to various stimuli than most people. This occurs with some individuals with autism spectrum disorders, especially in the realm of touch. For example, they may seek out heavy pressure, feeling calmed by being wrapped in a heavy blanket or otherwise "squeezed."

Idiopathic - Describing a disease of unknown or uncertain cause.

Inclusion - The use and participation by individuals with disabilities and their families of the generic services that are used by and are available to other individuals.

Incompetent - A person is incompetent if s/he is either too young or unable to manage his/her own affairs because of an impairment.

Independent Educational Assessment (IEA) - A parent has the right to obtain, at public expense, an independent educational assessment of the pupil from qualified specialists if the parent disagrees with an assessment obtained by t independent educational assessment he public education agency. The public agency may initiate a due process hearing to show that its assessment is appropriate.

Independent Living Skill Training or Independent Living Program - Provides training and support of people who want to live semi-independently or independently. Includes skill development in home care, cooking, money management, consumer shopping, etc.

Individuals with Disabilities Education Act (IDEA) - The Individuals with Disabilities Education Act (IDEA) is the federal law which, in the United States, guarantees a Free Appropriate Public Education (FAPE) is made available to eligible children. Protections under the law apply only to children with specific disabilities, including mental retardation, deafness, blindness, and autism.

Individualized Education Plan Program (IEP) - Required by Public Law 94-142, this plan is developed for individuals who are school-aged by a team of people such as parents, teachers and psychologists. The IEP describes the direction a student with special needs will be going in the future and how to get there.

Individualized Family Service Plan (IFSP) – A written plan for providing early intervention services to an eligible child and the child's family from birth up to the third birthday. The IFSP addresses developmental needs in at least one of the following areas: physical development, cognitive development, communication development, social or emotional development or adaptive development.

Individualized Program Plan (IPP) - This written plan is similar to an Individualized Education Program (IEP). They It outlines special services, goals and objectives for a person who needs individualized help because of a developmental disability. The Regional Center and the Consumer develop the IPP. Individualized Family Service Plan (IFSP) is developed by Regional Center and the family of an infant (up to age 3).

Infant Intervention (Also called Infant Stimulation or Infant Development Programs) - Refers to programs designed to provide early education for children (under age three) with developmental disabilities and training and support for their parents.

Inherited trait - A genetic trait passed on from parent to child.

In-Home Supportive Services (IHSS) - Chore helpers who work with people who have disabilities who live at home. The Public Authority for In Home Support Services provides a registry of names of persons who have been approved to provide In Home Support Services

Insomnia – A condition that is characterized by difficulty sleeping for a prolonged period of time; one of the symptoms of clinical depression as defined by the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV).*

Intake and Assessment - A process used by agencies to determine whether or not people are eligible for their services and what services are needed.

Integrated Setting: - Environments in which people with and without disabilities can live and work. Examples of integrated settings include residential neighborhoods, accessible social venues such as movies, nightclubs, or restaurants, churches and public transportation.

Intellectual Disabilities (ID) The term "intellectual disability" (ID) is used in place of "mental retardation" (MR) in response to the growing commitments to avoid using the latter term because of the stigma associated with that label. In addition, some people may have the diagnosis of a developmental disability, due to other functional limitations, but be without any cognitive impairment.

Interdisciplinary Team (IDT) - A group of people (parents, teachers, psychologists, social workers, and others) who are involved with a consumer in helping him/her get the services he/she needs by developing the IEP, IPP or IHP. Some individuals are mandated to be part of the team; others are by invitation of the consumer.

Intermediate Care Facility/Developmental Disability (ICF/DD) - A type of health facility (50 or more residents) that provides habilitation and developmental services, supportive medical and personal care, and occasional skilled nursing care to persons with developmental disabilities, who require less than 24-hour per day nursing care.

Intermediate Care Facility/Developmental Disability-Habilitative (ICF/DD-H) - A licensed residential health facility which has as primary purpose the furnishing of 24-hour personal care, developmental training, habilitative and supportive health services in a facility with 15 beds or less to residents with developmental disabilities.

Intermediate Care Facility/Developmental Disability - Nursing (ICF/DD-N) - A type of health facility (six or less residents) which serves people with developmental disabilities who have medical conditions which require more intensive nursing and/or medical care and treatment than those residing in ICF/DD-H facilities.

Intermittent Explosive Disorder - A psychiatric diagnosis characterized by discrete episodes of failure to resist aggressive impulses resulting in serious assaults or destruction of property. The degree of aggressiveness displayed during an episode is totally out of proportion to the situation at hand. Individuals with ASD may have similar "rage attacks" but would likely not receive this diagnosis because it is only given when such behavior is not accounted for by another condition.

Internalizing Symptoms - When psychologists refer to "internalizing symptoms," they are talking about the kind of symptoms that are associated with anxiety and depression. Examples include: being anxious or afraid, worrying about the future, feeling self-conscious, being nervous, or feeling sad. Some studies suggest internalizing symptoms may be more common in children and teenagers with ASD. In contrast are "externalizing symptoms" (i.e. aggression or impulsivity.)

Job Site Training - A component of supported employment services that involves direct and systematic instruction of job tasks and related vocational skills provided by a job trainer to a worker with a disability at a competitive job site.

Job Training Partnership Act (JTPA) (Public Law 97-300) - A government-funded program, which helps train people for work.

Joint Attention - The interaction involving two or more individuals as the result of a stimulus such as eye-gazing, finger-pointing or other verbal or non-verbal indication. The ability to follow another's gaze and share the experience of looking at an object or activity.

Lanterman Developmental Disabilities Act of 1976 - This California State law provides basic service rights to persons with developmental disabilities. It put in place the Department of Developmental Services, Regional Centers, the State Council on Developmental Disabilities and Area Boards to establish needed services and monitor their delivery.

Learning Disability (LD) A disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell or to do mathematical calculations.

Least Restrictive Environment (LRE) - A mandate established by federal and state laws and the courts that states that all people, regardless of disability, have the right to be served in ways and in places that allow a person to be as independent as possible with the least amount of supervision necessary.

Level of Care (LOC) - A term, used in the staffing standards for the developmental centers, which refers to staff who provide direct care, training, or supervision to clients.

Limited Conservatorship - A form of general conservatorship that applies only to adults with developmental disabilities who are, or could be, clients of California regional centers.

This protective legal arrangement is "limited" because the adult with a developmental disability retains the power to care for his/herself commensurate with his/her ability to do so.

Local Education Agency (LEA) Any local school district or Office of County Superintendent that has responsibility to provide special education services to eligible students.

Long Term Care (LTC) - A range of diagnostic, therapeutic, rehabilitative, supportive, and maintenance services to address the health, social, and personal needs of people who have restricted self-care capabilities. Services may be continuous or intermittent, but it is generally understood that they will be provided over a long period of time.

Lovaas Method - A time-intensive behavioral intervention developed by Dr. Ivar Lovaas that focuses on modifying behavior through a system of rewards and corrections; a form of Applied Behavior Analysis (ABA).

Low-Functioning Autism - Term used to refer to those on the autism spectrum who suffer relatively more impairment due to their disability compared to others. Individuals who are labeled as having a severe autism with cognitive impairment are individuals who have greater difficulty with social skills, and academic performance. These individuals may easily exhibit challenging behaviors, such as self-injury and aggression. This may be because they simply have not learned a better way of reacting or coping with the demands of daily stressors, or may have no better means for communicating with others. Children with severe autism may also engage in more sensory-related activities such as hand flapping, spinning, or rocking.

Low Incidence Disability – A severe, disabling condition with an expected incidence rate of less than one percent of the total enrollment. The conditions are hearing impairments, vision impairments, severe orthopedic impairments, or combination thereof.

Magnetic Resonance Imaging (MRI) - A non-invasive procedure that uses powerful magnets and radio waves to construct pictures of the body.

Mainstreaming - In educational settings, mainstreaming describes a way of working with students who have special needs on the same premises with regular students. It takes the help of support people like resource teachers and gives everyone a better chance at a regular education. There are various degrees of mainstreaming including integration (kids with disabilities participate in some of the regular classes) and full-inclusion (kids with disabilities are included in all classes with proper support and adaptations in their own neighborhood school).

Manic Depression - See Bipolar Disorder.

Melatonin - A natural substance produced by the body that regulates sleep. Melatonin supplements are often taken by people with insomnia.

Meltdown - A term for the loss of control experienced by a person with an autism spectrum disorder who is overwhelmed by social, emotional, sensory, or other stressful stimuli. May include screaming, kicking, hitting, throwing objects, biting, banging head into the wall or floor, collapsing to the floor, etc.; a tantrum.

Mental Retardation - Mental retardation is a condition diagnosed before age 18 that includes below-average general intellectual function, and a lack of the skills necessary for daily living. Mental retardation affects about 1 - 3% of the population. There are many causes of mental retardation, but doctors find a specific reason in only 25% of cases. Mental retardation may also be referenced as "cognitive impairment" or "intellectual disability."

Mild Autism - Term used to refer to those on the autism spectrum who suffer less impairment due to their disability compared to others.

Mind-Blindness - The condition of being unable to intuit others' plans, thoughts, and points of view; to have difficulty understanding other people's beliefs, attitudes, perspectives, and emotions.

Movement Therapy - Psychotherapeutic use of movement and/or dance to further emotional, social, cognitive, and physical integration of the individual.

Multiplex - A term used to refer to families that include more than one person with a certain disease or disorder. When autism researchers say they are studying *multiplex* families, they mean they are studying families that have more than one child with autism.

Multiply Handicapped - Having more than one disability requiring special services.

Music Therapy - The psychotherapeutic use of music to address an individual's physical, emotional, cognitive, and social needs.

Natural Environment - Places and social contexts commonly used by individuals without developmental disabilities.

Neurotypical - A newly developed term for those with a normally developed brain; non-disabled or non-autistic.

Negative Reinforcement - Negative reinforcement strengthens a behavior by reducing or removing something that is undesirable. For example, if taking an aspirin for a headache relieves the pain, an individual is more likely to take an aspirin in the future to relieve headache pain.

Neurodiversity - The notion, originally arising in the context of the autism community, that neurological differences should be viewed as gender or race are viewed --as examples of human variation. According to this perspective, autism should be thought of not as a disorder, but as a different way of being that should be accepted, and perhaps even celebrated; the idea that individuals should be valued, socially accepted, and have access to equal opportunity whether or not their brains are "typically" wired.

Neuroleptics - An alternate term for antipsychotic medications.

Neurologist - A physician is trained to investigate, or diagnose and treat disorders related to the human nervous system. The nervous system encompasses the brain, spinal cord, and peripheral nerves. Neurologists sometimes treat children with autism, especially those suffering with epilepsy (that is, seizures).

Neuropsychologist - A professional specializing in both neurology and psychology who is knowledgeable about brain structure, chemistry, and processing and how these impact human psychology and behavior; a brain-behavior specialist.

Neurotransmitter - A chemical that is released from a nerve cell; these chemicals transmit impulses from a nerve cell to another nerve, muscle, organ, or other tissue. Irregular neurotransmitter activity is often involved in mental illness, and many medications prescribed to treat conditions such as Depression or Bipolar Disorder alter the availability of one or more types of neurotransmitters. Neurotransmitters include dopamine, serotonin, and norepinephrine.

Noncontingent Reinforcement - A procedure that decreases the frequency of a behavior by both reinforcing alternative behaviors and extinguishing the undesired behavior. Since the alternative behaviors are reinforced, they increase in frequency and therefore compete for time with the undesired behavior.

Nondiscriminatory Evaluation - Refers to evaluating for disabilities in such a way as to not discriminate on the basis of race or culture. This is one of the requirements of the Individuals with Disabilities Education Act and is designed to minimize the potential for inaccuracies in evaluations to result in incorrect placement in educational programs.

Nonpublic Agency (NPA) - usually an individual or group certified by the State, to provide a specific special education service but who is not an employee of the public school system.

Nonpublic School (NPS) - A school which meets state standards to allow private placement of students for whom there is no appropriate public school placement available.

The Principle Of Normalization – This is a social concept originating in Scandinavia and developed by Wolf Wolfensberger in the United States. In practice, those services, which integrate people with special needs into everyday community life to enjoy all that we value for ourselves.

Obsessive Compulsive Disorder (OCD) - A psychiatric disorder characterized by recurrent obsessions or compulsions that are severe enough to consume more than one hour per day of a person's time or cause significant distress or impairment. Some children diagnosed with an autism spectrum disorder, or their family members, also may be diagnosed with obsessive compulsive disorder.

Occupational Therapist - A professional who uses productive or creative activity to maximize the functioning of physically or emotionally disabled people. Occupational therapists help an individual develop mental or physical skills that aid in daily living activities. They assess fine motor skills, age appropriate self-help skills (like dressing), and sensory issues (like hypersensitivity to touch).

Occupational Therapy (OT) - A discipline that aims to promote health by enabling people to perform meaningful and purposeful activities. Occupational therapists work with individuals who suffer from a mentally, physically, developmentally, and/or emotionally disabling condition by utilizing treatments that develop, recover, or maintain clients' activities of daily living. The therapist helps clients not only to improve their basic motor

functions and reasoning abilities, but also to compensate for permanent loss of function. The goal of occupational therapy is to help clients have independent, productive, and satisfying lives.

Olanzapine - Generic name for Zyprexa -- an antipsychotic medication prescribed for treatment of Bipolar Disorder and Schizophrenia. It is also sometimes used "off label" to treat the irritability, mood disturbance, and aggression associated with autism spectrum disorders.

One-on-One Aide - An alternate term for personal assistant.

Operant Conditioning - A type of learning in which voluntary behavior is strengthened if followed by a pleasurable consequence or lessened if followed by a negative consequence. In the case of operant conditioning, the learner associates his or her own actions with the consequences.

Orthopedically Handicapped (OH) Persons with specific orthopedic or physical needs which adversely affect their independence or capabilities.

Other Health Impaired (OHI) a person with a chronic medical impairment, such as asthma that significantly impacts their daily life and may hamper their functioning in the community.

Oxytocin - A hormone associated with social memory and attachment, maternal behavior, and human bonding. Researchers are looking into whether this hormone also may be associated with ASD.

Parkinsonism, medication-induced - A stiff gait and a tremor caused by medication; among the extrapyramidal side effects sometimes resulting from use of conventional antipsychotic medications.

Pass Cadre/Specialist - Individual who assists with the development of a PASS (Plan for Achieving Self Support). This social Security Administration specialist also approves submitted plans, monitors and modifies the plans as needed.

Peer Modeling - A technique in which children with an Autism Spectrum Disorder are grouped together with "typical" children in the hope that they will learn to imitate their peers' behaviors and social skills.

Peer Review - Pre-publication evaluation of a researcher's results and claims by a committee of others in the same field who are checking for scientific merit and accuracy. Peer review is generally required by academic and scientific journals.

People First - A self-advocacy organization with chapters across the state designed to promote empowerment of people with developmental disabilities.

People First Language – When speaking about people with a disability, use the practice of saying the word "people" first before referring to the disability, i.e., people or individuals with disabilities; a person with a developmental disability, etc.

Perseveration - In psychology, the uncontrollable repetition of a particular response, such as a word, phrase, or gesture, despite the absence or cessation of a stimulus. Examples in children with autism spectrum disorder include stacking or lining objects up for hours, or becoming fixated on a certain topic, such as trains or baseball statistics.

Person Outside the System (POS) – An individual with needs who does not qualify for services. (POS may also refer to "purchase of services")

Personal Assistant - One of the educational supports, called "supplementary aids and services" in the Individuals with Disabilities Education Act, designed to help maximize the potential of children with disabilities to be mainstreamed with children without disabilities.

Pervasive Developmental Disorder (PDD) Children with this diagnosis typically have many features of autism, such as severe and pervasive difficulties in social and communication behaviors, but do not meet the full criteria for Autistic Disorder. They may not have symptoms in each of the three categories or their symptoms may be milder.

Pervasive Developmental Disorder - Not Otherwise Specified - A diagnosis given when there is severe impairment in social interaction and verbal and nonverbal communication skills, or when stereotyped behavior, interests and activities are present, but symptoms do not meet the criteria for other autistic disorders.

Phenotype - Class to which an organism belongs as determined by the description of its physical and behavioral characteristics; in autism, this refers to the fact that the disorder is diagnosed based upon observable behavior rather than upon some biological marker or gene. Contrast to genotype.

Physical Therapist - A professional trained to treat disease, injury, and developmental delays using methods such as therapeutic exercise, heat, light and massage.

Physical Therapy (P.T.) - A health care profession that is concerned with identifying and maximizing quality of life and movement potential within the spheres of promotion, prevention, diagnosis, treatment/intervention,and rehabilitation. This encompasses physical, psychological, emotional, and social wellbeing.

Physically Handicapped or Physically Disabled (PH or PD) - - Students with specific orthopedic needs which adversely affect their educational participation or performance.

Pica - A behavior; compulsive eating of non-food items

Picture Exchange Communication System (PECS) - An augmented communication program intended to help children and adults with autism to acquire functional communication skills. It uses ABA-based methods to teach children to exchange a picture for something they want - an item or activity.

Pitocin - An artificial form of the hormone oxytocin, which can be used to induce labor and strengthen contractions.

Pivotal Response Training - Employs behavioral techniques to target core --or pivotal-- skills. The hope is that gains will be made in many areas if a child improves in a core

area such as becoming more motivated to connect socially, and to imitate. It is also hoped that these gains will generalize, that is, the child will demonstrate new behaviors and coping not just with the person teaching the skill, but at home, at play, and in all contexts.

Placebo - An inactive substance given to one group in a research study, while another group receives a new medication which is being tested; if the new medication is more effective than the placebo, its worth is proven. Alternately, a placebo is a substance containing no medication and prescribed or given to reinforce a patient's expectation to get well.

Placement - A service available to clients who would benefit from an out-of-home living arrangement and for those who are unable to live independently.

Positive Behavior Support Support that is specified in a behavior intervention plan that is developed by an IPP team to help a person with serious behavior problems change patterns of undesirable behaviors that interfere with learning. These supports are respectful of a person's dignity, and are successful in promoting a person's capabilities and opportunities. The support includes a reliance on data obtained from a functional analysis assessment.

Positive Reinforcement - Positive reinforcement strengthens a behavior by presenting a consequence that is desirable, such as food or praise. See negative reinforcement.

Prader-Willi Syndrome (PWS) - A genetic developmental disability in which infants are first characterized by poor muscle tone and feeding difficulties. As toddlers, the second phase of the syndrome is characterized by voracious appetites. Mental retardation, medical complications, and behavior problems are common.

Pragmatic Language - Refers to the "art of conversation": taking turns speaking, staying on a topic for a polite number of turns (even if it's not your favorite topic), showing interest in someone else's comments, etc. Individuals with ASDs, and particularly those with Asperger's Syndrome, are known to have difficulty with pragmatic language. Helping them to learn pragmatic language skills is often a part of speech therapy.

Prevalence - The total number of cases of a disease in a given community or population at a given time.

Private Industry Council (P.I.C.) - Local boards responsible for developing jobs and job training opportunities for persons with disabilities. Funds are provided through the JTPA (Job Training Partnership Act).

Probiotics - A supplement of live microorganisms that may beneficially affect the host upon ingestion.

Program Analysis Of Service Systems (P.A.S.S.) - A way of evaluating the quality of services for people who are at risk of being devalued and are dependent upon organizational services. A team of people use the tool to ask a series of questions about a service program. The answers provide direction for making services more normalized.

Program Development Funds (P.D.F.) - A combination of parental fees and money from the State Council on Developmental Disabilities available each year for starting new, innovative or expanded services.

Programming/Instruction - An organized process that leads an individual to develop the skills necessary for residential, social and vocational integration into the community.

Pronoun Reversal - A speech peculiarity that occurs when a person uses the pronoun for the second ("you") or third ("he/she") person when they actually mean the *first* person ("I" or "me"). For example, a child might say, "He wants juice" instead of "I want juice" when he's trying to get a caregiver to give him a drink. Children with autism often use pronoun reversal in their speech.

Proprioception - A sense, beyond the typical five (sight, smell, hearing, taste, touch), which involves knowing what your muscles and joints are doing and where you are in space; often discussed in the context of Occupational Therapy or Sensory Integration Therapy.

Prosody - Refers to how one speaks: tone, volume, and speed. Individuals with ASDs may have trouble imitating others' way of speaking so that they sound odd to "typical" people's ears. For example, they may speak in a monotone, or very fast, or as if they are delivering a lecture.

Protection and Advocacy, Inc. (PAI) - Federally funded under Public Law 95-602, PAI provides advocacy services for people with developmental disabilities. This service often includes the involvement of the legislature and the courts to ensure basic rights.

Prozac - A Selective Serotonin Reuptake Inhibitor (SSRI) often used to treat Depression, Obsessive-Compulsive Disorder, and other conditions. Brand name for fluoxetine.

Psychiatrist - A medical doctor (M.D.) who specializes in the prevention, diagnosis, and treatment of mental illness. They can prescribe medication, which psychologists cannot do.

Psychoactive Medication - Drugs that exert significant effects on mental functioning or behavior by altering the chemical makeup of the central nervous system.

Psychologist - A professional specializing in diagnosing and treating diseases of the brain, emotional disturbance, and behavior problems. Psychologists can only use talk therapy as treatment; a patient must see a psychiatrist or other medical doctor to be treated with medication.

Psychomotor Agitation - A restlessness evident to others; one of the symptoms of clinical depression as defined by the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV).*

Psychomotor Retardation - A feeling of slowing down, with signs that others can observe; one of the symptoms of clinical depression as defined by the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV).*

Psychosocial - Prefers to both psychological and social aspects of behavior.

Purchase of Service Agreement (POS) - Refers to the agreement between an agency and a vendor that allows the vendor to provide a service for a person with a developmental disability for pay.

Quality Assurance (QA) - A set of requirements that cover the major areas of client care and existence, including: programming focus and hours, client rights, community integration, health, the physical plant and safety, client records, staff training, and qualifications and administration.

Quetiapine – This is a generic name for Seroquel; an atypical antipsychotic medication that helps restore the balance of neurotransmitters in the brain. This medication, sometimes used to treat bipolar disorder or schizophrenia, can be used in autism spectrum disorder to improve concentration, minimize severity and frequency of mood swings, and ease nervousness.

Random Sample – This term refers to a group of people to be used in a research testing situation in which every person had an equal chance of being included in the sample. If a study or research project is not using a random sample, bias is introduced, which casts doubt on results.

Randomized - Refers to an experimental design in which a researcher does *not* control who gets put in the group receiving a new treatment and who is placed in the group receiving a placebo or standard treatment (also called a "control group"). Participants are assigned to whichever group by chance in order to eliminate bias.

Rapid Prompting Method – This is a behavioral intervention that uses a Teach-Ask paradigm for eliciting responses through intensive verbal, auditory, visual, and/or tactile prompts.

Reasonable Accommodation: - An adaptation or modification of the environment or materials which make it possible for a person with a disability to fully participate in an activity.

Receptive Language – This term refers to the ability to understand spoken language.

Recreational therapy - A therapy that uses treatment, education and recreation services to help people with illnesses, disabilities and other conditions to develop and use their leisure in ways that enhance their health, functional abilities, independence and quality of life.

Refrigerator Mother - Derogatory term based on the now debunked theory of psychologist Bruno Bettelheim who argued that autism was caused when a child withdrew from the unbearable rejection of a cold, unresponsive mother.

Regional Centers (RCs) - Regional centers are nonprofit private corporations that contract with the Department of Developmental Services to provide or coordinate services and supports for individuals with developmental disabilities. They have offices throughout California to provide a local resource to help find and access the many services available to individuals and their families. Regional centers provide diagnosis and assessment of eligibility and help plan, access, coordinate and monitor the services and supports that are needed because of a developmental disability. There is no charge for the diagnosis

and eligibility assessment. Regional Centers are contracted by the Department of Developmental Services. Twenty-one centers provide people with residential, day, transportation, and social, independent living, and respite, medical, psychological, preschool and other services.

Regression - Returning to a pattern of behavior or level of skill characteristic of a younger age. For example, a three-year-old child would be said to "regress" if he had begun to speak, and then lost that ability.

Rehabilitation Act of 1973 (Public Law 93-112) - A federal law that expands rehabilitation services to persons with severe disabilities. Section 504 of this law prohibits discrimination on the basis of handicap and mandates accessibility in all federally assisted programs and is considered, therefore, the federal "civil rights" act for people with disabilities.

Reinforcement - A consequence that causes a behavior to occur with greater frequency. For example, giving a child a break from work when he or she becomes disruptive may inadvertently increase the likelihood that the disruptive behavior will recur in the future.

Relationship Development Intervention - A program designed to help individuals with Autism Spectrum Disorders acquire "dynamic intelligence," that is, the ongoing, spontaneous ability to integrate many levels of experience and meaning to interact socially and to adapt to changing circumstances.

Repetitive Behaviors - Actions that one carries out over and over again, such as repeatedly spinning the wheel of a toy car around.

Residential Service Provider - A person or persons who provide a place to live and varying degrees of supervision for persons with developmental disabilities in community living arrangements such as staffed apartments, family homes, group homes, board and care homes, etc.

Respite - Temporary care of people who have developmental disabilities and are living at home. The period of rest provided to family members is a critical aspect of the home environment. This term also covers out-of-home respite.

Rett Syndrome - Rett Syndrome is a childhood neurodevelopmental disorder characterized by normal early development followed by loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, gait abnormalities, seizures, and mental retardation. It affects females almost exclusively. Individuals with Rett Syndrome often exhibit autistic-like behaviors.

Risperdal - Brand name for risperidone --an anti-psychotic drug used to treat problem behaviors associated with autism such as irritability, aggression, temper tantrums, self-injury, and quickly changing moods. It was approved by the U.S. Food and Drug Administration (FDA) for use in children and adolescents with autism in October, 2006.

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Rocking - The act of rythmically moving one's body back and forth or side to side; one of the repetitive and possibly self-stimulating behaviors associated with individuals having an autism spectrum disorder.

Savant - A person who, although developmentally or mentally handicapped, possesses extraordinary skills in a certain area such as calculation, memory, music, or art.

Savant Syndrome – This is a condition in which a person, though developmentally or mentally handicapped, possesses extraordinary abilities in one specific area such as calculation, memory, music, or art. Savant Syndrome is often associated with autism.

Schizophrenia - A psychiatric disorder characterized by marked social or occupational dysfunction. Symptoms can include delusions, hallucinations, and disorganized speech.

Second-Generation Antipsychotics - The newest antipsychotic medications, such as Risperdal; most have been widely used since the 1990s and generally do not cause the extrapyramidal side effects common with the use of conventional antipsychotics. However, second-generation antipsychotics are associated with other possible side effects such as increased appetite and weight gain.

Section 504 - The section of the U.S. Rehabilitation Act of 1973 designed to protect the rights of individuals with disabilities in programs and activities that receive federal funds from the U.S. Department of Education. Section 504 requires a school district to provide a "free appropriate public education" (FAPE) to each qualified student with a disability who is in the school district's jurisdiction, regardless of the nature or severity of the disability. Although valuable, this protection is less than that afforded to an individual whose disability is covered under the Individuals with Disabilities Education Act (IDEA).

Segregation - The congregation of people with special needs in daytime programs and/or living situations where there is little or no interaction with people who do not have disabilities and are not paid to be there. This is the opposite of integration.

Seizure - The physical results of abnormal electrical discharges in the brain, which can include convulsions, sensory disturbances, or loss of consciousness.

Self Advocacy - The awareness, motivation, and ability of an individual to represent and communicate his or her own interests, to exercise personal choice, to exert control over his or her environment and to avoid exploitation and abuse.

Self-Care - Providing for or meeting one's physical and personal needs such as dressing, grooming and hygiene, without being dependent on others.

Self-Injurious Behavior – This refers to any behavior that can cause self-inflicted physical damage, such as bruises, redness, and open wounds. Some common forms of these behaviors are head-banging, hand-biting, and excessive scratching or rubbing.

Self-Selecting - Participants in research are considered to be "self-selecting" when they volunteer to participate in a study.

Sensory Integration Therapy - A treatment used to help children, including those with Autism Spectrum Disorders, who have motor, sensory, and perceptual difficulties. It is

based on the belief that you can change the brain by changing experience. If a person has poor sensory integration –which then impacts the ability to function and learn—you can provide sensory experiences that will improve not only sensory integration itself, but overall functioning. Providers of Sensory Integration Therapy are most often Occupational Therapists.

Seriously Emotionally Disturbed (SED) - An individual who has severe problems relating to others; who is unable to learn for reasons other than intellectual functioning, who is severely aggressive or extremely withdrawn.

Seroquel – This is a brand name for quetiapine; an atypical antipsychotic medication that helps restore the balance of neurotransmitters in the brain. This medication, sometimes used to treat bipolar disorder or schizophrenia, can be used in autism spectrum disorder to improve concentration, minimize severity and frequency of mood swings, and ease nervousness.

Sertraline - A Selective Serotonin Reuptake Inhibitor (SSRI) often used to treat Depression, Obsessive-Compulsive Disorder, and other conditions. Generic name for Zoloft.

Service Coordination – Locating and coordinating support, information and service choices for a consumer and the family to feel secure, knowledgeable, responsible and empowered. Also known as Case Management.

Service Provider - An individual, group or agency approved by the State Department of Developmental Services to supply a service for a fee to a regional center client.

Severe Autism - Term used to refer to those on the autism spectrum who suffer relatively more impairment due to their disability compared to others.

Sheltered Employment - A program offering long-term employment to people who are exempt from federal wage and hour laws because of disability. By Department of Labor standards, "sheltered workers" must receive pay based on productivity relative to typical workers doing the same job. These programs are usually segregated, but need not be.

Short-Term Objective - Included on the student's IEP/IPP as a means of measuring progress toward a goal. It includes a series of intermediate steps or training activities that will take the student/consumer from his or her current level of functioning to the accomplishment of annual goals.

Simplex - A family with only one child with a certain disease or disorder. When autism researchers say they are looking only at *simplex* families, for example, they mean they want to study only families that have one child with autism rather than more than one.

Single Photon Emission Computed Tomography – An imaging system which generates three-dimensional images of a person's particular organ or body system. SPECT detects the course of a radioactive substance that is injected, ingested, or inhaled. In neurology, a SPECT scan is often used to visualize the brain's cerebral blood flow and thereby, indicate metabolic activity patterns in the brain.

Site-Based Program - A program where the majority of classes and activities occur in a site (building) as opposed to occurring in the community.

Skilled Nursing Facility (SNF) - A health facility or a distinct part of a hospital which provides nursing care and supportive care to patients whose primary need is for skilled nursing care on an extended basis. It provides 24-hour inpatient care and as a minimum, includes medical, nursing, dietary and pharmaceutical services, and an activity program. (The acronym is sometimes pronounced "sniff.")

Social Anxiety Disorder/Social Phobia - An individual with this psychiatric disorder has a persistent fear of social or performance situations to such a marked degree that it interferes with his or her daily life. Most often, the individual avoids the situation, or endures it with a feeling of dread. Symptoms may include tremors, sweating, muscle tension, blushing, and other signs of anxiety.

Social/Recreation Program - Programs that train people to participate in social and recreational activities on their own.

Social Reciprocity - The give-and-take of social interaction; social reciprocity depends upon one's ability to read the cues, intentions, feelings, and perspectives of others. A key feature of autism spectrum disorders is a lack of ability to read such cues and intentions leading to a deficit in social reciprocity.

Social Scripts - A social skills training technique to teach individuals with ASDs "scripts" for common social situations. The individual initially uses a support, such as a reminder card with the script available to read, and then gradually lessens reliance on the support until he or she can use the scripted question or phrase spontaneously.

Social Security Administration (SSA) - The federal agency that administers both the Supplemental Security Income (SSI) Program and the Social Security Disability Insurance Program.

Social Security Disability Insurance (SSDI) - Benefits paid to insured workers under the Social Security program who have become disabled.

Social Skills Group - These groups use a variety of social skills training techniques and offer an opportunity for individuals with ASDs to practice social skills with each other and/or typical peers on a regular basis during group meetings.

Social Skills Training - Encompasses different approaches to teaching the building blocks of social behavior and interaction. Strategies for addressing the social deficits that characterize autism are varied, ranging from role-playing desirable and undesirable social behavior, to social stories, to social skills groups including children with ASD and typical peers.

Social Stories - A social skills training tool for children with autism spectrum disorders; social stories break a social situation down into understandable parts and make clear social cues and expectations that children with ASDs cannot pick up naturally due to the nature of their disability.

Special Education - People and practices helping to provide individualized learning experiences for students with special needs.

Special Education Local Planning Area (SELPA) - The local unit responsible for administering the comprehensive special education plan in that area.

Special Incident Report (SIR) – An SIR is a formal report that is filed with the regional center whenever a person served by the regional center is involved in an unusual event, such as a crime or injury. There are detailed and specific rules about SIRs that service providers and regional centers must follow.

Special Services - Residential facilities where extra funds have been provided to offer extra services for the people who live there. These services include behavior modification, vocational training and independent living.

Speech and Language Therapy - A planned program for people who have problems with speech or language to help them communicate with others by voice or symbol systems.

Speech-Language Pathologist (SLP) - A professional who is trained to assess and treat issues in communication. These may include articulation (pronunciation of sounds), receptive language (understanding and processing what is communicated by others), expressive language (the ability to communicate to others), fluency (including stuttering), voice problems (including pitch and intonation), and pragmatics (the social use of language).

Speech Therapist - An older term for a Speech-Language Pathologist --a professional who is trained to assess and treat issues in communication. These may include articulation (pronunciation of sounds), receptive language (understanding and processing what is communicated by others), expressive language (the ability to communicate to others), fluency (including stuttering), voice problems (including pitch and intonation), and pragmatics (the social use of language).

Squeeze Machine - A device created by Temple Grandin, a high functioning person and author with autism, which exerts deep pressure all along the body; it is said to calm anxiety.

Staffing Ratio - The numerical relation of the number of direct care staff on duty to the number of clients in attendance.

State Council on Developmental Disabilities - Under the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 95-602) and the Lanterman Developmental Disabilities Services Act of 1976, the State Council has a responsibility to plan and coordinate resources to protect the legal, civil and service rights of persons with developmental disabilities. The Council is made up of consumers, parents and state agency administrators.

Stereotypic Behaviors - Constant repetition of certain apparently meaningless movements or gestures, e.g., rocking or head banging.

Stimming - Short for "self-stimulation", a term for behaviors which stimulate one's own senses, such as rocking, spinning, or hand-flapping.

Strattera - Brand name for atomoxetine; a non-stimulant medication approved by the FDA for the treatment of Attention Deficit Hyperactivity Disorder (ADHD) in children, adolescents, and adults.

Substantial Gainful Activity - "Substantial" work activity means the performance of significant physical and/or mental duties, which are productive. "Gainful" activity is work for pay or profit or intended for profit.

Suicidal Ideation - Having thoughts of suicide or of taking action to end one's own life. Suicidal ideation includes all thoughts of suicide, both when the thoughts include a plan to commit suicide and when they do not include a plan. Antidepressants, sometimes used in the treatment of autism, have been linked to potential suicidality in teens and young adults.

Supplemental Security Income (SSI) - Money that comes from the federal government to people who, because of their disabilities, don't earn enough to support themselves.

Support Services - Those services designed to meet the total needs of the individual that are not traditionally met in a residential or day program (e.g., physical, speech, occupational therapy).

Supported Employment - A term used to describe a system of support for people with disabilities in regards to ongoing employment in integrated settings. Supported employment provides assistance such as job coaches, job development, job retention, transportation, assistive technology, specialized job training, and individually tailored supervision. Supported Employment often refers to both the development of employment opportunities and on-going support for those individuals to maintain employment.

Supported Living - Services and supports provided by an agency to enable an individual with developmental disabilities to live in their own home in the community. Most often, these supports are more intensive than that of independent living services.

Surrogate Parent - A person who is appointed by the District or SELPA to act as a child's parent in all matters related to special education. A surrogate is appointed when a child is a dependent or ward of the court, and the court has limited the rights of the parent/guardian to make educational decisions, or when a parent cannot be identified or located

Susceptibility Gene - A gene that predisposes a person to having a certain condition. There are some autism researchers who are trying to find out if there might be one or more autism susceptibility genes.

Systemizing – A theory that classifies people on the basis of their scores along two dimensions: empathizing (E) and systemizing (S). E-S theory was developed by British psychologist Simon Baron-Cohen as a major reconceptualization of cognitive sex differences in the general population; and in an effort to understand why the cognitive difficulties in autism appeared to lie in domains in which on average females

outperformed males and why cognitive strengths in autism appeared to lie in domains in which on average males outperformed females.

Tegretol - A drug used to prevent and control seizures; may also be used to treat certain mental/mood conditions (e.g. Bipolar Disorder, Schizophrenia) and certain types of nerve pain. Generic name for Carbamazapine.

Thalidomide - Once given to treat morning sickness, Thalidomide was banned in pregnant women because it led to birth defects. Recently, it also has been associated with autism.

Theory of Mind - Refers to the notion that many autistic individuals do not understand other people have their own desires, thoughts, and points of view. To lack a "theory of mind" is to suffer from "mind-blindness."

Therapeutic Recreation - A therapy that uses treatment, education and recreation services to help people with illnesses, disabilities and other conditions to develop and use their leisure in ways that enhance their health, functional abilities, independence and quality of life.

Therapy - Improving, developing or restoring functions impaired or lost through illness, injury or deprivation. Therapy may address a variety of functions (e.g., physical, speech, and occupational therapy) and may take a variety of forms (e.g., art, dance, music therapy).

Thorazine - Brand name for chlorpromazine; one of the conventional antipsychotic medications, which were developed in the 1950s, '60s, and '70s and commonly caused extrapyramidal side effects.

Title 17 - A portion of the California Code of Regulations that contains the Department of Developmental Services' regulations as well as other regulations. These regulations, starting with Section 50201, cover parental fees, conflict of interest, rules for conducting research, clients rights, fiscal audits and appeals, fair hearings, vendorization procedures, regional center administrative practices and procedures, standards and rate-setting procedures for community-based programs and in-home respite services, residential facility care and supported living services.

Title 22 - A portion of the California Code of Regulations that contains the state licensing regulations for community care facilities and health facilities, as well as other regulations.

Toe-walking - Describes a gait pattern of toe-to-toe rather than normal heel-to-toe walking; common in children with autism.

Tourette's Disorder - A disorder in which a person develops multiple motor tics and one or more vocal tics. Motor tics are involuntary, sudden, repetitive movements such as eye-blinking, nose twitching, or stamping. Vocal tics often accompany motor tics. They are also involuntary, and include things like grunting, throat clearing, or chirping. These movements should be distinguished from the type of repetitive, stereotyped behaviors common to those with an Autism Spectrum Disorder (ASD), although it is possible for a person to have both ASD and Tourette's Disorder.

Traumatic Brain Injury (TBI) – an acquired injury to the brain caused by an external physical event resulting in total or partial functional disability or psychosocial impairment that adversely affects a person's abilities.

Transition – This term refers to the passage from one program, setting or environment to another, i.e., graduation from a high school program into a work environment or other significant changes.

Trichotillomania - An impulse-control disorder in which a person will, especially when anxious, pull hair from their head, eyebrows, eyelashes, or body. Some people with trichotillomania report feeling soothed by the activity, and are usually unable to stop it without therapy, medication, or both.

Tuberous Sclerosis - A genetic disorder caused by mutations in one of two genes, causes benign tumors and lesions to form in many different organs of the body, including the brain, skin, eyes, heart, kidneys, and lungs. The impact it has on those who have it is extremely variable. Some are so mildly affected, they go undiagnosed. Others suffer severe impairments which may include seizures, mental retardation, and autism.

Typical Peers - Essentially refers to "typically developing peers," a term perhaps more meaningful than "normal peers."

Valproate - An anti-epileptic, anti-convulsant medication. Generic name for depakene.

Vendor/Provider - A person, program or facility, which has been vendorized (authorized) by a regional center to provide a particular services to regional center clients.

Vendorization - The process used to verify that an applicant meets all of the requirements and standards pursuant to the regulations prior to the provision of services to clients.

Verbal Behavior (VB) - An intervention, often seen as an adjunct to Applied Behavioral Analysis, which is directed towards helping children on the autism spectrum develop language. Verbal Behavior attempts to capture a child's motivation to develop a connection between the value of a word and the word itself. This may be an improvement over traditional ABA which focuses on labeling objects rather than spontaneous use of language.

Vestibular - Refers to a sense, in addition to the typical five (sight, hearing, smell, taste, touch), which is related to the inner-ear and involves your awareness of movement, head position, and balance; often discussed in the context of Occupational Therapy or Sensory Integration Therapy.

Video Modeling - A technique in which videos of real people and situations are used to model behavior sequences, interpersonal relationships, friendship behaviors, and perspective-taking to children with autism.

Visual Schedule - A tool used to help organize individuals with autism by presenting the abstract concept of time in a concrete form according to age and understanding. Pictures or photos showing a toothbrush (for brushing teeth), clothes (for getting dressed), and a backpack (for getting ready to go to school) are examples of items that would appear on a

schedule helping to organize morning routine for a child not yet able to read. For older children, the schedule may appear in written form.

Visually Handicapped or Visually Impaired (VH or VI) - A visual impairment which, even with correction, adversely affects a student's educational performance. The term includes both partial sightedness and blindness.

Vitamin A - An antioxidant vitamin; beta-carotene and retinol are both forms of Vitamin A.

Vitamin B6 - A water-soluble vitamin that is important for metabolism and the immune system.

Vitamin C - An antioxidant vitamin.

Vocational Rehabilitation (VR) - Helps people prepare for and find employment. Also sometimes synonymously used as Department of Rehabilitation.

Vocational Services - Services, including education and training that enable each individual to develop a capacity to work and progress as far as possible from vocational functions to affordable employment in the community. Such services include vocational evaluation, counseling, activity services, work adjustment, occupational skill, training and job placement.

Weighted Blanket - A blanket made to be extra heavy in order to provide deep pressure; used for Sensory Integration Therapy.

Weighted Vest - A vest made to be extra heavy in order to provide deep pressure; used for Sensory Integration Therapy.

Work Activity Program (WAP) - Regional Centers Department of Rehabilitation (Habilitation Section) fund and monitor those programs for people who have acquired basic vocational and independent living skills and need a work-oriented setting to prepare for a vocation. In practice, these programs are usually segregated but need not be. Work Activity Program (WAP) services through the Department of Rehabilitation include paid work, work adjustment and supportive habilitation services in a sheltered work shop setting. WAPs provide paid work in accordance with Federal and State Fair Labor Standards. Work adjustment services may include developing good work safety practices, money management skills, and appropriate work habits. Supportive habilitation services may include social skill and community resource training as long as the services are necessary to achieve vocational objectives.

Work Incentives - Polices or procedures created to address barriers to employment caused be benefits eligibility and promote self-sufficiency

Work Incentives Planning & Assistance Project (WIPA) - These projects operate in a variety of locations throughout the country. They provide community presentation on Social Security Administration Work Incentives and Benefits Planning. Additional they provide individualized benefits counseling and on-going benefits management/

Yeast Free Diet - Diet that eliminates yeast; these often exclude natural and refined sugars (including fruit) and fermented foods such as bread, vinegar, alcohol, cheese, soy sauce, coffee, and processed meats.

Zero Exclusion - An entry criteria philosophy that states that no one should be denied services in the particular program, regardless of the level and degree of disability, or the number of secondary disabilities.

Ziprasidone - Generic name for Geodon; an atypical antipsychotic medication used to treat psychiatric disorders, such as schizophrenia, and symptoms associated with bipolar disorder. This medication helps restore the balance of neurotransmitters in the brain. When used in the treatment of autism spectrum disorder, ziprasidone can ease nervousness and help improve concentration.

Zoloft - A Selective Serotonin Reuptake Inhibitor (SSRI) often used to treat Depression, Obsessive-Compulsive Disorder, and other conditions. Brand name for sertraline.

Zyprexa - Brand name for Olanzapine, an antipsychotic medication prescribed for treatment of Bipolar Disorder and Schizophrenia. It is also sometimes used "off label" to treat the irritability, mood disturbance, and aggression associated with autism spectrum disorders.

A Glossary of Acronyms

AAC	Augmentative and Alternative Communication
AAMR	American Association on Mental Retardation
AB	Area Board
AB	Assembly Bill
ABA	Applied Behavior Analysis
ACA	Assembly Constitutional Amendment
ACDD	Accreditation Council on Services to Persons with Developmental Disabilities
ACR	Assembly Concurrent Resolution
ADA	Americans with Disabilities Act
ADA	Average Daily Attendance
ADC	Adult Development Center
ADD	Administration on Developmental Disabilities
ADD	Attention Deficit Disorder
ADHC	Adult Day Health Care
AD/HD	Attention Deficit/Hyperactivity Disorder
ADOS-G	Autism Diagnostic Observational Schedule - Generic
AFDC	Aid to Families With Dependent Children
AIT	Auditory Integration Training
AJR	Assembly Joint Resolution
ANDI	A Normalization and Development Instrument
AOR	Assembly Office of Research
ARC	Association for Retarded Citizens (Arc also)

ARCA	Association of Regional Centers
ARC - C	Association for Retarded Citizens - California
Arc	The Arc (San Francisco and The Arc - National) Formerly titled ARC
AS	Asperger's Syndrome
ASDs	Autism Spectrum Disorders
AWIC	Area Work Incentive Coordinator
B&C	Board and Care
BAP	Broad Autism Phenotype
BCP	Budget Channel Proposal
BPAO	Benefits Planning & Outreach Program or Specialist
BSE	Behavioral Summarized Evaluation
CAC	California Adult Council
CAC	Community Advisory Committee
CAHF	California Association of Health Facilities
CAHSEE	California High School Exit Exam
CAL-SAC	California Society for Autistic Children
CAL-TRANS	California Department of Transportation
CANHC	California Association for Neurologically Handicapped Children
CAPH	California Association of Physically Handicapped
CAPSES	California Association of Private Special Education Schools
CARCH	California Association of Residential Facilities
CARF	Commission on the Accreditation of Rehabilitation Facilities
CARH	Community Assistance for the Retarded and Handicapped
CARR	California Association of Residential Resources
CARS	Childhood Autism Rating Scale
CASH-PCR	California Association of State Hospital Parent Councils for the Retarded
CASP	California Association of Service Providers
CBI	Community Based Instruction
CBT	Cognitive Behavioral Therapy
CC	Community College
CCA	Community Action Agency
CCF	Community Care Facility
CCS	California Children's Services (formerly Crippled Children's Services)
CDD	Childhood Disintegrative Disorder
CDER	Client Development Evaluation Report
CEC	Council on Exceptional Children
CES	California Epilepsy Society
CF	Cystic Fibrosis
CFC	Combined Federal Campaign
CFR	Code of Federal Regulations
CHAD	Combined Health Agencies Drive
CHDP	Child Health and Disability Prevention
CHP	Comprehensive Health Planning
CIL	Center for Independent Living
COLA	Cost of Living Adjustment
CP	Cerebral Palsy
CPC	Client Program Coordinator

CPEC	California Postsecondary Education Commission
CPP	Community Placement Plan
CPS	Community Program Specialist
CRA	California Rehabilitation Association
CRA	Clients Rights Advocate
CSLA	Community Supported Living Arrangement
CWIC	Community Work Incentive Coordinator
DCH	Developmental Centers for the Handicapped
DD	Developmental Disabilities
DDS	Department of Developmental Services
DHH	Deaf and Hard of Hearing (HOH)
DHS	Department of Human Services
DME	Durable Medical Equipment
DOE	Department of Education
DOF	Department of Finance
DOH	Department of Health Services
DOR/DR	Department of Rehabilitation
DREDF	Disability Rights Education Defense Fund
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
DSP&S	Disabled Students Program and Services
DSS	Department of Social Services
DSS	Disabled Student Services
DTAC	Day Training and Activity Center
ED	Emotional Disability/Disturbance
EDD	Employment Development Department
EEG	Electroencephalogram
EI	Early Intervention
EPSDT	Early Periodic Screening Treatment and Diagnosis
FAPE	Free Appropriate Public Education
FBA	Functional Behavioral Assessment
FC	Facilitated Communication
FCT	Functional Communication Training
FRC	Family Resource Center
FY	Fiscal Year
GA	General Assistance
GA	Governmental Affairs
GAC	Governmental Affairs Committee
GSA	General Services Administration
HFA	High Functioning Autism
HHS	Health and Human Services
HR	House Resolution
HSP	Habilitation Services Program
HSP&S	Handicapped Student Program and Services
HUD	Housing and Urban Development
HWA	Health and Welfare Agency
ICE	Integrated Competitive Employment
ICF/DD-H/N	Intermediate Care Facility/Developmentally Disabled - Habilitative/Nursing
ICF/MR	Intermediate Care Facility - Mentally Retarded

IDEA	Individuals with Disabilities Education Act
IDT	Interdisciplinary Team
IEP	Individualized Education Program
IFSP	Individual Family Service Plan
IHP	Individualized Habilitation Plan
IHSS	In-Home Support Services
ILC	Independent Living Center
ILP	Independent Living Program
ILSP	Independent Living Services Program
IPP	Individualized Program Plan
IQ	Intelligence Quotient
IRWE	Impairment Related Work Expense
ITP	Individualized Transition Plan
JAN	Job Accommodation Network
JTPA	Job Training Partnership Act
LAC	Legislative Advisory Committee
LAO	Legislative Analysts Office
LEA	Local Education Agency
LD	Learning Disability
LMU	Local Member Unit
LOC	Level of Care
LPS	Lanterman-Petris-Short
LRE	Least Restrictive Environment
LTC	Long Term Care
LTCF	Long Term Care Facility
MCH	Maternal and Child Health
MD	Muscular Dystrophy or Medical Doctor
MH	Multiply Handicapped or Mentally Handicapped
MHAB	Mental Health Advisory Board
MI	Mental Illness
MIS	Management Information System
MR	Mental Retardation
MRI	Magnetic Resonance Imaging
MS	Multiple Sclerosis
NADD	National Association for the Dually Diagnosed
NADDC	National Association of Developmental Disabilities Councils
NASMRPD	National Association of State Mental Retardation Program Directors
NEARC	National Conference of Executives of Associations for Retarded Citizens
NHA	National Health Agency
NISH	National Industries for the Severely Handicapped
NIH	National Institutes of Health
NIMBY	"Not in my back yard"
NISH	National Industries for the Severely Handicapped
NPA	Non Public Agency
NPS	Non Public School
NT	Neurotypical
O & M	Orientation and Mobility
OAB	Organization of Area Boards
OAH	Office of Administrative Hearings

OAL	Office of Administrative Law
OCD	Obsessive Compulsive Disorder
ODEP	Office of Disability Employment Policies
OEO	Office of Economic Opportunity
OH	Office of the Handicapped
OHDS	Office of Human Development Services
OJT	On the Job Training
OSE	Office of Special Education
OSERS	Office of Special Education and Rehabilitation Services
OSHA	Occupational Safety and Health Administration
OT	Occupational Therapy
OT/PT	Occupational Therapy/Physical Therapy
PAI/P&A	Protection and Advocacy, Inc.
PAC	Political Action Committee
PASS	Program Analysis of Service Systems
PASS	Plan for Achieving Self-Sufficiency
PCMR	President's Committee on Mental Retardation
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
PDF	Program Development Fund
PECS	Picture Exchange Communication System
PIC	Private Industry Council
PKU	Phenylketonuria
PL	Public Law
PL-ADOS	Pre-Linguistic Autism Diagnostic Observation Schedule
POS	Person Outside the System
POS	Purchase of Service Agreement
PRT	Pivotal Response Training
PSE	Post Secondary Education
PT	Physical Therapy
PWS	Prader-Willi Syndrome
QA	Quality Assurance
RAC	Rehabilitation Advisory Committee
RC	Regional Center
RCOM	Regional Center Operations Manual
RDI	Relationship Development Intervention
RFP	Request for Proposals
ROP	Regional Occupational Program
RSA	Rehabilitation Services Administration
RRDP	Regional Resource Development Plan
SB	Senate Bill
SCA	Senate Constitutional Amendment
SCDD	State Council on Developmental Disabilities
SCR	Senate Concurrent Resolution
SDC	State Developmental Center
SE	Sheltered Employment or Supported Employment
SED	Seriously Emotionally Disturbed
SELPA	Special Education Local Planning Agency
SJR	Senate Joint Resolution

SLP	Speech Language Pathologist
SNF	Skilled Nursing Facility
SOCCO	Society of Care-Home Operators
SOAR	Sufficiency of Allocation Report (Regional Centers)
SOP	Summary of Performance
SOR	Senate Office of Research
SPECT	Single Photon Emission Computerized Tomography
SRS	Social Responsiveness Scale
SSA	Social Security Administration or Social Services Agency
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
SSP	State Supplementary Program
STE	Supported Training - Enclave
STI	Supported Training - Individual
SWITP	School to Work Interagency Transition Partnership
TANF	Temporary Assistance to Needy Families
TASH	The Association for Persons with Severe Disabilities
TDD	Telecommunications Device for the Deaf
TEACCH	Treatment and Education of Autistic and Related Communication-Handicapped Children
TPP	Transition Partnership Program
TTY	Teletype – keyboard device to access telephone services for deaf people
UCPA	United Cerebral Palsy Association
USBLN	United States Business Leadership Network
USC	United States Code
VOC ED	Vocational Education
VR	Vocational Rehabilitation
WI	Workability One
WII	Workability Two
WIII	Workability Three
WIV	Workability Four
WAC	Work Activity Center
WAP	Work Activity Program
WIA	Workforce Investment Act
WIB	Workforce Investment Board
WIIP	Work Incentives Improvement Plan
WIPA	Work Incentives Planning & Assistance Project
WOTC	Work Opportunity Tax Credit

Section 4. Statewide Self-Advocacy Network

Statewide Self-Advocacy Network

Coming Soon!

Vision Mission Values

SSAN will build a statewide peer advocacy network that links advocates, communities, regions and statewide leadership.

For decades, local, regional and statewide self and peer advocacy groups and organizations have worked to enhance quality of life and protect the rights of Californians with disabilities. By building on these existing structures to link information and goals, the network will lessen fragmentation of effort and increase collective advocacy.

SSAN will join self-advocacy efforts across communities and move advocacy by persons with disabilities to the forefront in California.

Invited Partners

- Association of Regional Center Agencies
- California Foundation for Independent Living Centers
- Department of Developmental Services
- Disability Rights California
- People First of California
- State Council on Developmental Disabilities
- UCEDD (UCLA, USC, UC DAVIS)

Statewide Self-Advocacy Network

How it Works

With multi-year outcome-driven plans, advocacy leadership, strategies and tools will be exchanged. SSAN representatives and their communities identify regional advocacy interests and needs. Together they create community-based goals, objectives and carry out activities to achieve their outcomes.

SSAN will meet quarterly in Sacramento for leadership training, sharing expertise, evaluating tools and reporting on progress with community advocacy plans.

Statewide Self-Advocacy Network

Statewide Communication

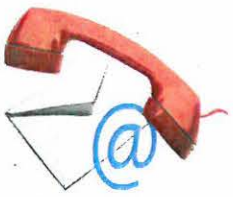
SCDD will maintain SSAN web pages on its website where each region will have opportunities to highlight advocacy activities. Information sharing will be encouraged. Self-advocates, families and the community will have access to materials, tools, and presentations.

Statewide Self-Advocacy Network

SCDD is providing funding for facilitation support to assist SSAN with organizational and leadership development and training.

Support will include assistance to SSAN members and their facilitators to prepare quarterly reports regarding community issues, leadership development and progress toward outcomes. SSAN materials and tools will be provided in understandable formats and available through the SCDD website.

Each year SCDD and SSAN members will publish an online report and video of goals, activities and outcomes.



Carol Risley, Executive Director
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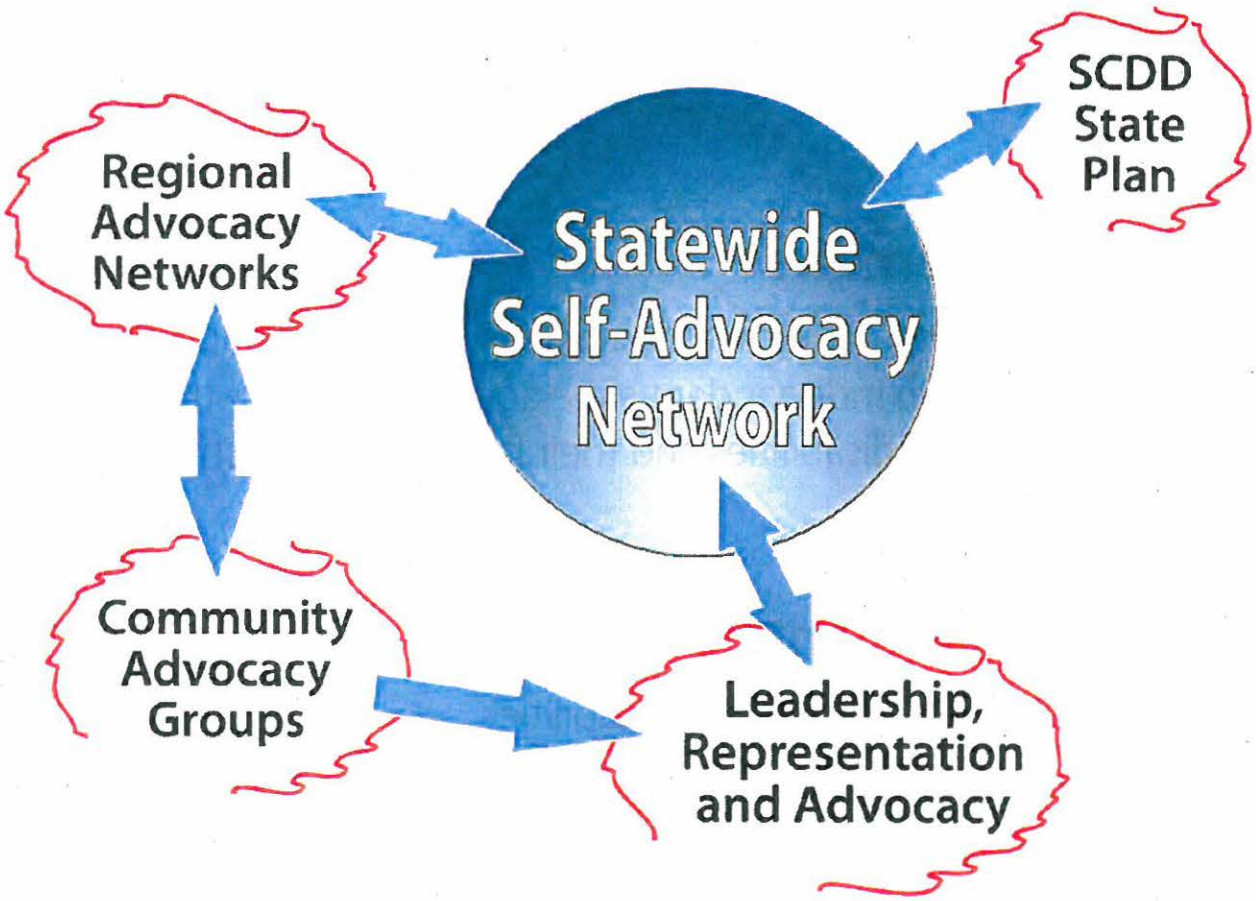
SSAN

Statewide Self-Advocacy Network



Statewide Self-Advocacy Network

1507 21st Street, Suite 210 Sacramento, CA 95811

SCDD

Thank you to members of the State Council and Area Boards on Developmental Disabilities for their commitment to advocacy lead by Californians with disabilities. This booklet describes how the Statewide Advocacy Network will ensure self and peer advocates lead by example to impact change.

Carol Risley, Executive Director

Mission Statement

State Council on Developmental Disabilities (SCDD) is established by state and federal law as an independent state agency to ensure that people with developmental disabilities and their families receive the services and supports they need.

Acknowledgements

State Council on Developmental Disabilities

State Council Self-Advocates Advisory Committee

Area Boards on Developmental Disabilities

Booklet contributors:

Jennifer Allen

Lisa Cooley

Molly Kennedy

Jimmy Lee

Robert Taylor

BOARD RESOURCE CENTER
PO Box 601477, Sacramento, CA 95860
916-574-1023 • brcenter.org

The California State Council on Developmental Disabilities advocates, promotes and implements policies and practices that achieve self-determination, independence, productivity and inclusion in all aspects of community life for Californians with developmental disabilities and their families.

SSAN
Statewide Self-Advocacy Network

The Statewide Self-Advocacy Network will build an alliance of self-advocates that links California communities with statewide organizations to advance civic participation and advocacy by persons with disabilities.

This booklet describes construction of a vibrant statewide system of advocacy that enables interchange, practical learning and leadership across the state.

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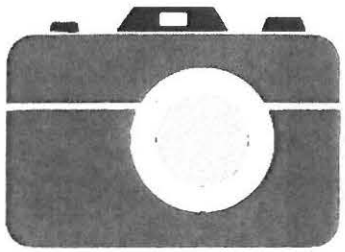
Statewide Self-Advocacy Network

Snapshot



The Network is a newly created framework that will unify, centralize and strengthen the efforts of existing advocacy groups that operate in the State of California.

Each of the 13 regions and identified statewide advocacy organizations will select a representative to participate in quarterly leadership trainings and meetings. Representatives will bring current and long-term advocacy interests and goals to the statewide meetings. Network members will provide progress reports on community-based projects. Multi-year outcome driven plans will be established and tracked.

The Council will maintain Network web pages on its website where each region will have opportunities to highlight advocacy activities. Information sharing will be encouraged. Self-advocates, families and the community will have access to materials, tools, and presentations.

The Council will provide funding for facilitation support to assist the Network with leadership and organizational development. Network materials and tools will be provided in understandable formats and available through the Council's website.

The Network will join self-advocacy efforts across communities and move advocacy by persons with disabilities to the forefront in California.

Introduction

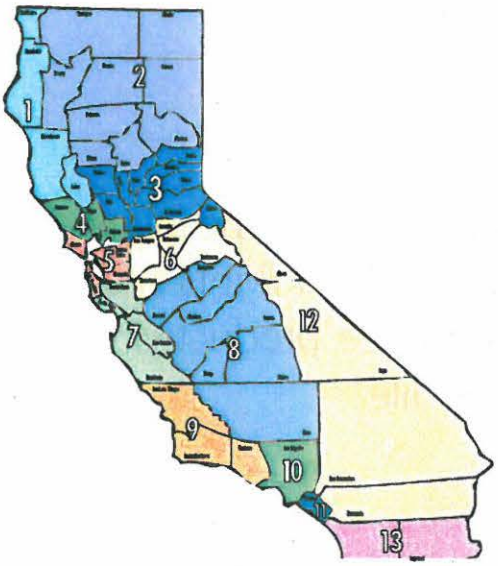
Molly Kennedy

Who should be leading the advocacy movement? Individuals with disabilities want to be treated with respect and be in charge of their lives so it begins with their voices leading. To earn true equality, we have to advocate for ourselves and not let others, though well meaning, determine our course.

Everyone with developmental disabilities needs to see themselves as an advocate. Understand what it takes to be an advocate and how to build these skills. Each individual should advocate not only for their own needs, but for system changes that benefit everyone

Introduction

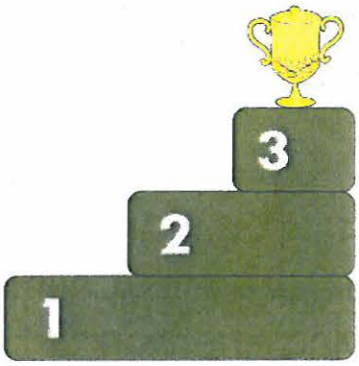
Established by state and federal law to ensure people with developmental disabilities and their families receive the services they need, State Councils on Developmental Disabilities are funded by the federal Administration on Developmental Disabilities (ADD). Every State Council develops a five-year state plan and implements activities designed to improve the availability and quality of services for persons with developmental disabilities. To accomplish their objectives, State Councils utilize strategies such as training, building coalitions, educating policymakers, barrier elimination and funding projects that address priority areas.



The California State Council on Developmental Disabilities (Council) is unique in having a network of 13 regional offices, known as Area Boards on Developmental Disabilities, leading community-based activities. Because of the size, complexity, and diversity of California, it is critical to include local communities in both the development and implementation of the State Plan. Through area boards, the Council assists with advocacy, training, coordination, and achievement of State Plan goals. Regional and statewide outcomes are reported to the California legislature and federal government.

Introduction

Central to accomplishment of the Council's mission is an active commitment to leadership by persons with disabilities in personal and public advocacy. By supporting the development of the Statewide Self-Advocacy Network—**Network**—with strong local roots and effective regional representation, the Council seeks to strengthen pathways to change led by persons with disabilities.



State Council's goal #1:

"Individuals with developmental disabilities have the information, skills, opportunities and support to advocate for their rights and services and to achieve self determination, independence, productivity, integration and inclusion in all facets of community life."

The complete State Plan is located on the Council's website at

http://www.scdd.ca.gov/

Purpose

Lisa Cooley

I want to create a world where the word "inclusion" is not just a concept for people who have developmental disabilities. For too many decades, people with all kinds of disabilities – but specifically developmental disabilities – have been on the fringes of life and not really fully included.

Call it tokenism, if you must. We have only been included because it is the legally appropriate thing to do, or it's the feel good thing. I want not only our state, but the world, to do better than that.

Purpose

Human rights apply to all persons and carry a pledge of equal opportunities to life and liberty. The Convention on the Rights of Persons with Disabilities (CRPD), the first human rights treaty of the 21st century, strengthens obligations that ensure persons with disabilities are included in society and supported to build their capacities. The belief underlying self and peer advocacy is that informed decision-making and civic engagement promote environments where persons with disabilities can enjoy real equality.

The Network assists individuals who rely on California's human service systems to direct efforts that result in more Californians with disabilities exercising fundamental freedoms.

For more information on the treaty go to
http://www.un.org/disabilities/

To view CRPD videos go to
http://brcenter.org/lib/SP_TR_CRPD.php

Purpose

For decades, local, regional and statewide self-advocacy organizations have worked to improve the quality of life and protect the rights of Californians with disabilities. By uniting these efforts, the Network will lessen fragmentation and increase the impact of advocacy action.

The Network addresses evolving local and statewide advocacy interests with practical approaches that reflect the needs of the people they represent. Plans are outcome-driven with activities and accomplishments reported to the Council, legislature and federal government.

Purpose

The Council is committed to supporting self-advocates to build the Network so together they may expand:

- **Personal leadership**
  Choosing a direction in life and taking action.

- **Civic Engagement**
  Working to make a difference in the community and developing the knowledge and skills to make that difference. Promoting quality of life in a community through political and non-political processes.

- **Peer Representation**
  Speaking or acting on behalf of other people with disabilities.

- **Advocacy**
  The political process of influencing public policy to advance the interests of people with disabilities.

Background

Jennifer Allen

I believe the self-advocacy network would be an important tool for all persons with disabilities in California. It will bring together self-advocates and organizations around the table to create a new avenue in the advocacy community.

The network will expand on the methods that have been used up until now. We already have some things in place, but now more information and tools will be available.

Background

In 2011, the Administration on Developmental Disabilities (ADD) convened a Self-Advocacy Summit in Los Angeles to solicit state and national recommendations for strengthening self-advocacy across the country. The California team (self-advocates representing the Council, Disability Rights California, People First of California, and University Centers for Excellence in Developmental Disabilities) recommendations focused on:

- Statewide Network
- Area Boards to support self-advocacy outcomes in communities
- Statewide coalition building and peer-led participation
- Statewide self-advocacy resource library

Suggestions by the California team also reflected national recommendations:

1) ADD Consumer Advisory Committee or national task force

2) user-friendly websites for self-advocacy information

3) more influence in public policy

4) disability awareness

5) outreach to youth and underserved communities

Background

Building on the ADD Summit recommendations and California's self-advocacy accomplishments, the Council called for invigorated collaboration among local, regional and statewide organizations to carry out the State Plan.

Goal #1:
Individuals with developmental disabilities have the information, skills, opportunities and support to advocate for their rights and services and to achieve self determination, independence, productivity, integration and inclusion in all facets of community life.

1. Promote stability and expansion of a statewide self-advocacy network, ensuring local delegates participate effectively in statewide meetings and events.
2. Strengthen existing self-advocacy groups and promote establishment of new groups at the local level.
3. Help to educate self-advocates so they are better able to assert their human, service and civil rights, prevent abuse, neglect, sexual and financial exploitation and be better informed.
4. Collaborate with local and statewide groups to promote and support the efforts of cross-disability and youth disability organizations to expand and strengthen their leadership network.
5. Support and train self-advocates to become effective trainers and facilitators.

Statewide Partnerships

Accomplishing meaningful advocacy—personal, peer or public policy—requires partnerships. The responsibilities of Network members will foster a collaboration of shared information and action. Invited partners include:

ARCA

Association of Regional Center Agencies

California Foundation for Independent Living Centers

Department of Developmental Services

Disability Rights California

People First of California

SCDD

State Council on Developmental Disabilities

Universit y Centers for Excellence in Developmental Disabilities

UCLA

UCLA

USC University of Southern California

USC

UCDAVIS UNIVERSITY OF CALIFORNIA

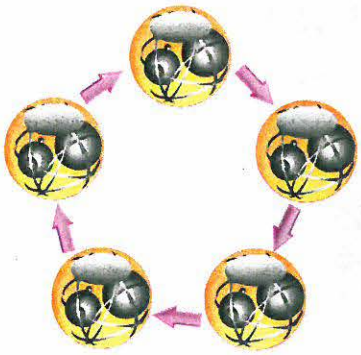
UC DAVIS

Robert M. Taylor

For peer and self advocates to point the way, for groups and organizations to be successful, they have to be leaders in the decision-making. If you are a leader that sets the example, people will follow your lead, and when you do it, things come out good for you!

When you are a leader, it is a great learning experience. Good leaders who belong to groups and organizations, know how to get things done, and can succeed.

How it Works



Structure

The Network promotes advocacy linkages among community, regional and statewide leaders:

- One representative from each statewide organization
- One representative from each of 13 area board regions

Organizational Responsibilities

- Provide facilitation to Network members to carry out activities
- Assist communication between the Network and advocacy groups
- Help create statewide and regional advocacy plans
- Support advocacy plan activities

Network Member Responsibilities

- Attend quarterly meetings
- Collaborate to create statewide and regional advocacy plans
- Carry out advocacy activities with local, regional and statewide organizations
- Collect information and contribute to Network reports
- Utilize and share strategies and tools

How It Works

Network Strategies

1. Statewide meetings to focus on core leadership areas and advocacy interests identified by members.

2. Think–Plan–Do decision-making process to learn and lead by example.

3. Community building through local and statewide advocacy planning and implementation.

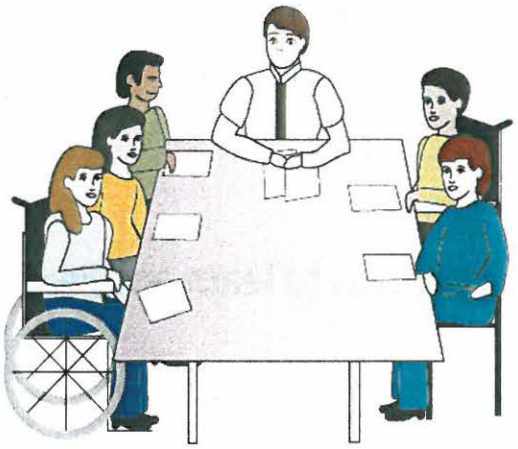
4. Resource exchange through Network web pages on Council's website where members and regions highlight tools and activities.

5. Accessible formats, plain language and multi-media tools.

6. Annual reporting about Network activity and outcomes.

7. Utilization of communication technologies.

Coordination



The Network meets quarterly over two days for leadership training, sharing expertise, planning and reporting on progress.

- Training to learn and practice leadership skills to share in communities. Members initiate personal and peer leadership goals that lead to community and statewide advocacy outcomes.

- Creating and following up on advocacy plans and assignments. Members share experiences and report on activities.

- Prioritizing statewide activities for policy making and systemwide advocacy.

How it Works

As a leader, it is important to understand firsthand the meaning of self-determination and how to exercise basic rights to a better quality of life. To gain practical experience in leadership, Network members determine their own personal and professional advocacy goals and carry out plans. Steering the statewide advocacy Network, members promote teamwork and expand expertise.

Leading by example means:

- Demonstrating personal change that others may follow
- Sharing learning experiences and teaching tools
- Advocating for the rights of others, not only for oneself
- Reaching out to others and respecting differences

Drawing on their own experiences, Network members increase their skills as community and statewide leaders. With increased engagement in their communities, individuals with disabilities take the lead to:

- Link self and peer advocacy efforts across the state
- Advocate with local, state and national policy-makers
- Impact local, state and national policies

Support

The Council supports Network meetings quarterly and provides:

- Travel related costs
- Meeting facilitation and leadership training
- Self-Advocacy Resource Room
- Network web pages and additional online resources
- Network leadership materials for community use
- Guidance and training materials for facilitators to support network members
- Follow through with plan development, implementation and reporting
- Network materials and tools designed in accessible formats

Outcomes & Evaluation

Jimmy Lee

The time has come for the outside world to recognize us as human beings. For too long, we have been treated as trouble makers, a burden, scapegoats, outcasts and rejects. I will make the unheard voices be heard.

I will speak loud and clear for those who can't.

Outcomes & Evaluation

Outcomes

1. Network members expand:
   - Personal leadership accomplishments
   - Civic engagement
   - Peer representation
   - Advocacy and statewide leadership
2. Network establishes stable membership and operating rules, with regular participation by members in community and statewide advocacy.
3. Network demonstrates use of multi-media and accessible formats for complex information, available to Network members, advocacy groups and the general community.
4. Increased Network influence in public policy making and presence.

Outcomes & Evaluation

Evaluation

1. Network member progress reports on leadership.

2. Annual Network Summit to review progress, accomplishments, effective strategies and areas for advancement.

3. Annual Network report to Council, in booklet and video formats.

Resources

The Council is developing a sustainable advocacy resource center that provides online and published resources to support self and peer advocacy across California. Self-advocates, families and the general community are encouraged to access all materials, tools and presentations.

Website

- Statewide Self-Advocacy Network web pages – Activities, materials and reports with highlights of local and regional advocacy activities
- Statewide advocacy and leadership resource center

Council Advocacy Resource Room

- 1507 21st Street, Suite 210 Sacramento, CA 95811

Section 5. Employment First

CALIFORNIA STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

EMPLOYMENT FIRST

Executive Summary

A vision of Californians with developmental disabilities working in integrated competitive employment.

August 2011

Executive Summary

"Community inclusion is fundamental to the whole idea of individuals with developmental disabilities finding jobs and choosing the 'best' support (natural or paid) to maintain employment.

School age children must be included in their school and community when they are young. That's the foundation we build everything on.

Work leads to health and well-being – self-esteem, confidence, and more income. Also important it leads to increased social networks and making contributions to the greater community like paying taxes and having buying power."[1]

Legislation

Chapter 231, Statutes of 2009 (Assembly Bill 287) was signed into law on October 11, 2009 and directs the State Council on Developmental Disabilities to:

- Form a standing Employment First Committee;
- Develop an Employment First policy;
- Identify the respective roles and responsibilities of state and local agencies in enhancing integrated and gainful employment opportunities for individuals with developmental disabilities;
- Identify strategies, best practices, and incentives for increasing integrated employment and gainful employment opportunities for individuals with developmental disabilities, including, but not limited to, ways to improve the transition planning process for students 14 years of age or older, and to develop partnerships with, and increase participation by, public and private employers and job developers;
- Identify existing sources of employment data and recommend goals for, and approaches to measuring progress in, increasing integrated

[1] Consumer Subcommittee, Employment First Committee, January 6, 2011

employment and gainful employment of individuals with developmental disabilities;

- Recommend legislative, regulatory, and policy changes for increasing the number of individuals with developmental disabilities in integrated employment, self-employment, and microenterprises, and who earn wages at or above minimum wage, including, but not limited to, recommendations for improving transition planning and services for students with developmental disabilities who are 14 years of age or older;
- By July 1, 2011, and annually thereafter, provide a report to the appropriate policy committees of the Legislature and to the Governor describing its work and recommendations. The report due by July 1, 2011, shall include the proposed Employment First policy.

California Trends in Employment[2]

Individuals with developmental disabilities are much less likely to have the opportunity to work than individuals without disabilities and earn less than half what the general population earned from working.[3] Additionally, supports that would help individuals with developmental disabilities achieve integrated competitive employment are not always available or are at insufficient levels.

The majority of working age adults with developmental disabilities is supported in segregated non-work programs or facility based employment. Data from 2009 reflect the following:

- While there are no specific data in California for working age individuals with developmental disabilities, approximately 70% of working age adults in California are in the workforce (either employed or unemployed), as compared to 30% working age adults with any disability and 20% working age adults with a "mental disability".[4]
- 15% of individuals with developmental disabilities served by the Department of Developmental Services (DDS) were provided services in

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[2] The 2009 data reported here are the core elements of the Institute for Community Inclusion's IDD Agency National Survey of Day and Employment Services. These data focus on participation in integrated employment, community-based non-work, and facility-based services.

[3] American Community Survey, 2009

[4] Defined as difficulty learning, remembering, or concentrating.

integrated employment; 70% community based non-work settings; 15% facility-based work and non-work.

- 26.5% of working age individuals with developmental disabilities live below the poverty line versus 13% of the general population.
- The mean weekly earnings of individuals with a cognitive disability at closure from Vocational Rehabilitation Services were $212.
- In 2007, individuals without a disability nationally earned a mean weekly wage of $771 as opposed to $223 for individuals with developmental disabilities in California.
- Educators, adult service agencies and service providers face barriers to collaboration, including a lack of knowledge about each other's systems and bureaucratic constraints that complicate service coordination.
- No one state or local agency is responsible for charting out cross system services, identifying gaps or measuring progress on the employment status of individuals with developmental disabilities (occupation, hours worked, salary, job maintenance or promotion, service setting and benefits received).

Employment First Committee

In response to the legislative mandates, the Council formed an Employment First Committee (EFC) in September 2010. The EFC is composed of service recipients, state agencies, and advocacy organizations. In addition to the official committee, interested parties were invited to and actively participated in the EFC deliberations. Representatives included self-advocates, family organizations, state agencies, service providers, and a union representing employees.[5] Further, all meetings were noticed and conducted in accordance with the Bagley-Keene Open Meeting Act.[6]

At its initial meeting, the EFC and other interested parties formed five subcommittees to address barriers to employment, public benefits and employment, employer issues, innovative strategies, and transition from high school to adult life. Each subcommittee gathered information and developed proposed strategies designed to enhance employment

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[5] Please see Appendix E for a detailed roster.
[6] California Government Code Section 11120 et seq.

opportunities for individuals with developmental disabilities. Those strategies form much of this report.

Recommended Employment First Policy for California

It is the policy of the State of California that integrated competitive employment[7] is the priority outcome for working age individuals with developmental disabilities.

In plain language:

WORK IS FOR ALL

Issues, Goals, and Recommendations

Employment First is about focusing on real jobs, real wages, and real business settings for individuals with developmental disabilities to have the ability to increase their income and benefits, accrue assets and build wealth. The present work builds on the foundation laid by Chapter 397, Statutes of 2006 (SB 1270) that articulated core values and the need for expanded opportunities for individuals with developmental disabilities to work and participate in the community alongside their fellow citizens. Individuals with developmental disabilities are best suited to identify their own unique needs and how to best address those needs. Therefore, the services and supports provided must be individualized, culturally responsive, flexible and supportive of choice, change and control. For those individuals who receive services through the developmental disabilities system, the Employment First policy establishes a vision and direction while respecting the individual planning process as articulated in the Lanterman Developmental Disabilities Services Act.

The implementation of an Employment First policy will require a shift in policies and rebalancing of existing resources across all relevant state agencies (education, employment, health, disability and human services) to

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[7] Employment includes all income generation activities such as traditional jobs and owning one's own business.

support and encourage integrated employment outcomes, including self-employment and microenterprises. The following goals and objectives provide recommendations on policies, procedures, and practices in order to promote an employment first approach and document outcomes so as to measure success.

Interagency Collaboration and Coordination

Issue: Interagency coordination assists youth and adults with developmental disabilities who have needs across multiple agencies to gain access to services and supports for integrated employment. There are collaborative efforts in place; however, there is no overall framework for state or local agency collaboration and coordination. As a result, individuals with developmental disabilities do not have the necessary linkages, services, and supports they need.

Goal: Evaluate and reform existing state laws, regulations, guidelines, and operational procedures to institute systemic changes that increase agency collaboration and coordination toward the employment of individuals with developmental disabilities. These recommendations should increase interagency collaboration to develop an infrastructure to support and further employment as a priority outcome.

- Review current laws and regulations to determine if they can be strengthened to ensure adequate collaboration among the Departments of Education, Employment Development, Rehabilitation, and Developmental Services, school districts, regional centers, service and support providers, and employers to promote, develop, and support work experience, training, and on-the-job training for students with developmental disabilities.
- Maximize system efficiency through interagency collaboration and coordination between California Departments of Education (CDE), Rehabilitation (DOR), Developmental Services (DDS), Employment Development (EDD) and the California Community College Chancellor's Office (CCCCO) focused on the transition of youth and working age adults with developmental disabilities into integrated competitive employment.
- Strengthen regulations and processes that encourage the blending and braiding of funds between CDE, DOR, DDS, EDD, and CCCCO to

ensure seamless collaborative strategies for better employment outcomes.

- Identify and disseminate promising practices from partnerships such as DOR's College to Career Program where community colleges are providing inclusive education, job preparation, and placement services for integrated competitive employment.
- Coordinate the availability and usage of assistive technology across systems for individuals with developmental disabilities.
- Develop and implement evaluation strategies to determine effectiveness of models for interagency collaboration and coordination.
- Review and analyze existing employment data and develop and implement a system to establish benchmarks and measurable outcomes for the number of individuals with developmental disabilities that are competitively employed in integrated settings including self-employment and microenterprise.

Transition

Issue: A high proportion of students with developmental disabilities leave high school without being employed in integrated competitive employment or attending postsecondary education. While federal and state laws require school districts to provide transition planning and services, many stakeholders reported transition to be an especially problematic area. There is a significant need to adequately prepare students and their families to understand the range of available possibilities and facilitate transition to integrated gainful employment.

Goal: To ensure that students with developmental disabilities are adequately prepared for integrated competitive employment.

- Ensure that transition planning and services for students begins early in secondary school and such services should be included in individualized education programs (IEP), individualized transition plans (ITP), and individualized plans for employment (IPE).
- Ensure that all relevant agencies and partners participate in the transition planning process.
- Students must have opportunities to explore all postsecondary options, including college and other post-school training for employment.

- Provide students with opportunities for career exploration and preparation through peer mentoring work-based learning, internships, volunteer opportunities, and paid employment.

Getting Work

Issue: The majority of working age individuals with developmental disabilities is not in the labor force.

Goal: All working age youth and adults with developmental disabilities will have the choice and opportunity to work in jobs that are integrated within the general workforce and work side-by-side with co-workers with and without disabilities, earning benefits and competitive wages, or to engage in self-employment or microenterprise.

- Employment related training, services, and supports should target areas of present and future workforce growth with direct input from employers.
- Increase opportunities for individuals with developmental disabilities to pursue self-employment and the development of micro-enterprises or small businesses.
- Ensure supports are provided as needed and that generic resources, including natural supports within the family, community, and work setting are included as much as possible.
- Showcase parts of the system that are demonstrating success with implementing an employment first agenda through planning, service provision, job preparation and placement, removal of systems barriers, and provision of supports.
- Provide training and technical assistance to develop knowledge and skills for providers, job developers, job coaches, and agencies and employers to use best, promising, and emerging practices to provide employment related services and supports.

Benefits

Issue: Some mechanisms exist for individuals with developmental disabilities to maintain public benefits while working. However, individuals with developmental disabilities, their families, and service providers are often not fully aware of those mechanisms. This lack of knowledge sometimes serves as a disincentive to work.

Goal: Individuals with developmental disabilities, their families, and service providers will have access to resources that fully inform them of ways to maintain benefits while working if needed. Any disincentives to working caused by the actual or perceived risk of losing benefits will be reduced.

- Individuals with developmental disabilities understand the impact of work on their public benefits.
    - This includes overcoming the barrier of a lack of outreach to individuals with developmental disabilities about work and benefits. Therefore, information must be provided, in plain language, to working age individuals with developmental disabilities including those in transition from school to adult life.
- Make public benefits more flexible to support working individuals with developmental disabilities.
- Ensure that all agencies involved in assisting individuals with developmental disabilities obtain and maintain integrated competitive employment, including self-employment and microenterprise, provide accurate advice and resources concerning the interplay between public benefits and work.
- Evaluate and reform existing state laws, regulations, guidelines, operational procedures and funding practices to institute systemic changes that eliminate any disincentives caused by the risk of losing benefits when working if needed.

Supports

Issue: There are supports available to individuals with developmental disabilities to obtain and maintain employment. However, the various agencies responsible for serving individuals with developmental disabilities in their employment goals do not do so in collaboration with each other which results in supports that are frequently inadequate to meet the needs of individuals with developmental disabilities. Additionally, employers lack advice and information on the benefits of employing individuals with developmental disabilities and how to provide accommodations and supports.

Goal: Provide adequate supports to individuals with developmental disabilities in obtaining and maintaining integrated competitive employment, including self-employment and microenterprise.

- Provide regional center service coordinators with employment training from experts to instruct them on the available supports to individuals with developmental disabilities in obtaining and maintaining employment.
- Provide a dedicated employment specialist at each regional center, to enhance the level of information about employment and related issues available to individuals with developmental disabilities, families, service coordinators, and employers.
- Provide training for employers on how to appropriately accommodate individuals with developmental disabilities.

Section 6. Legislation

OVERVIEW OF LEGISLATIVE PROCESS

The process of government by which bills are considered and laws enacted is commonly referred to as the Legislative Process. The California State Legislature is made up of two houses: the Senate and the Assembly. There are 40 Senators and 80 Assembly Members representing the people of the State of California. The Legislature has a legislative calendar containing important dates of activities during its two-year session.

Idea

All legislation begins as an idea or concept. Ideas and concepts can come from a variety of sources. The process begins when a Senator or Assembly Member decides to author a bill.

The Author

A Legislator sends the idea for the bill to the Legislative Counsel where it is drafted into the actual bill. The draft of the bill is returned to the Legislator for introduction. If the author is a Senator, the bill is introduced in the Senate. If the author is an Assembly Member, the bill is introduced in the Assembly.

First Reading/Introduction

A bill is introduced or read the first time when the bill number, the name of the author, and the descriptive title of the bill is read on the floor of the house. The bill is then sent to the Office of State Printing. No bill may be acted upon until 30 days has passed from the date of its introduction.

Committee Hearings

The bill then goes to the Rules Committee of the house of origin where it is assigned to the appropriate policy committee for its first hearing. Bills are assigned to policy committees according to subject area of the bill. For example, a Senate bill dealing with health care facilities would first be assigned to the Senate Health and Human Services Committee for policy review. Bills that require the expenditure of funds must also be heard in the fiscal committees: Senate Appropriations or Assembly Appropriations. Each house has a number of policy committees and a fiscal committee. Each committee is made up of a specified number of Senators or Assembly Members.

During the committee hearing the author presents the bill to the committee and testimony can be heard in support of or opposition to the bill. The committee then votes by passing the bill, passing the bill as amended, or defeating the bill. Bills can be amended several times. Letters of support or opposition are important and should be mailed to the author and committee members before the bill is scheduled to be heard in committee. It takes a majority vote of the full committee membership for a bill to be passed by the committee.

Each house maintains a schedule of legislative committee hearings. Prior to a bill's hearing, a bill analysis is prepared that explains current law, what the bill is intended to do, and some background information. Typically the analysis also lists organizations that support or oppose the bill.

Second and Third Reading

Bills passed by committees are read a second time on the floor in the house of origin and then assigned to third reading. Bill analyses are also prepared prior to third reading. When a bill is read the third time it

is explained by the author, discussed by the Members and voted on by a roll call vote. Bills that require an appropriation or that take effect immediately, generally require 27 votes in the Senate and 54 votes in the Assembly to be passed. Other bills generally require 21 votes in the Senate and 41 votes in the Assembly. If a bill is defeated, the Member may seek reconsideration and another vote.

Repeat Process in other House

Once the bill has been approved by the house of origin it proceeds to the other house where the procedure is repeated.

Resolution of Differences

If a bill is amended in the second house, it must go back to the house of origin for concurrence, which is agreement on the amendments. If agreement cannot be reached, the bill is referred to a two house conference committee to resolve differences. Three members of the committee are from the Senate and three are from the Assembly. If a compromise is reached, the bill is returned to both houses for a vote.

Governor

If both houses approve a bill, it then goes to the Governor. The Governor has three choices. The Governor can sign the bill into law, allow it to become law without his or her signature, or veto it. A governor's veto can be overridden by a two thirds vote in both houses. Most bills go into effect on the first day of January of the next year. Urgency measures take effect immediately after they are signed or allowed to become law without signature.

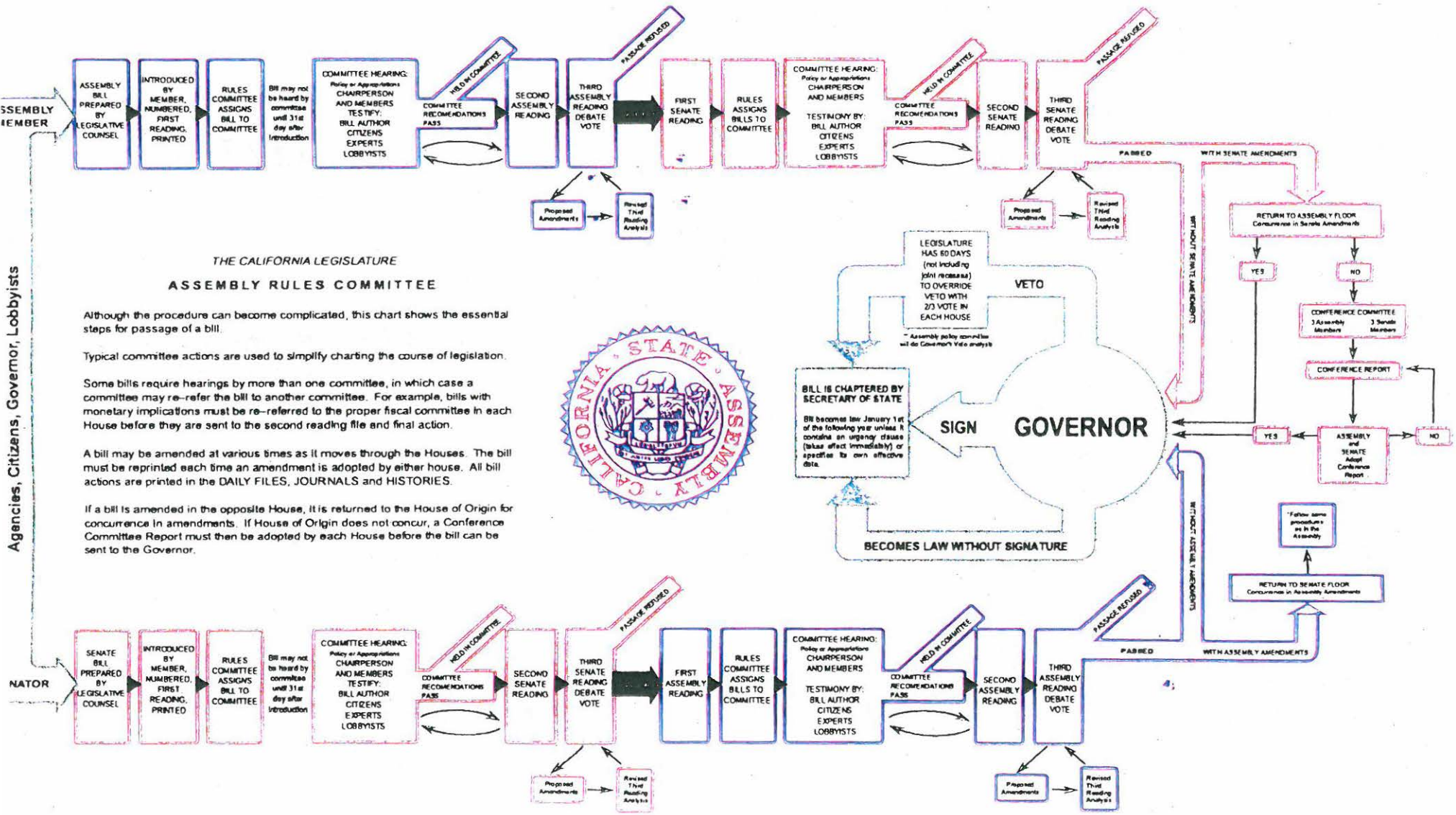
California Law

Bills that are passed by the Legislature and approved by the Governor are assigned a chapter number by the Secretary of State. These Chaptered Bills (also referred to as Statutes of the year they were enacted) then become part of the California Codes. The California Codes are a comprehensive collection of laws grouped by subject matter.

The California Constitution sets forth the fundamental laws by which the State of California is governed. All amendments to the Constitution come about as a result of constitutional amendments presented to the people for their approval.

THE LIFE CYCLE OF LEGISLATION

From Idea into Law



THE CALIFORNIA LEGISLATURE

ASSEMBLY RULES COMMITTEE

Although the procedure can become complicated, this chart shows the essential steps for passage of a bill.

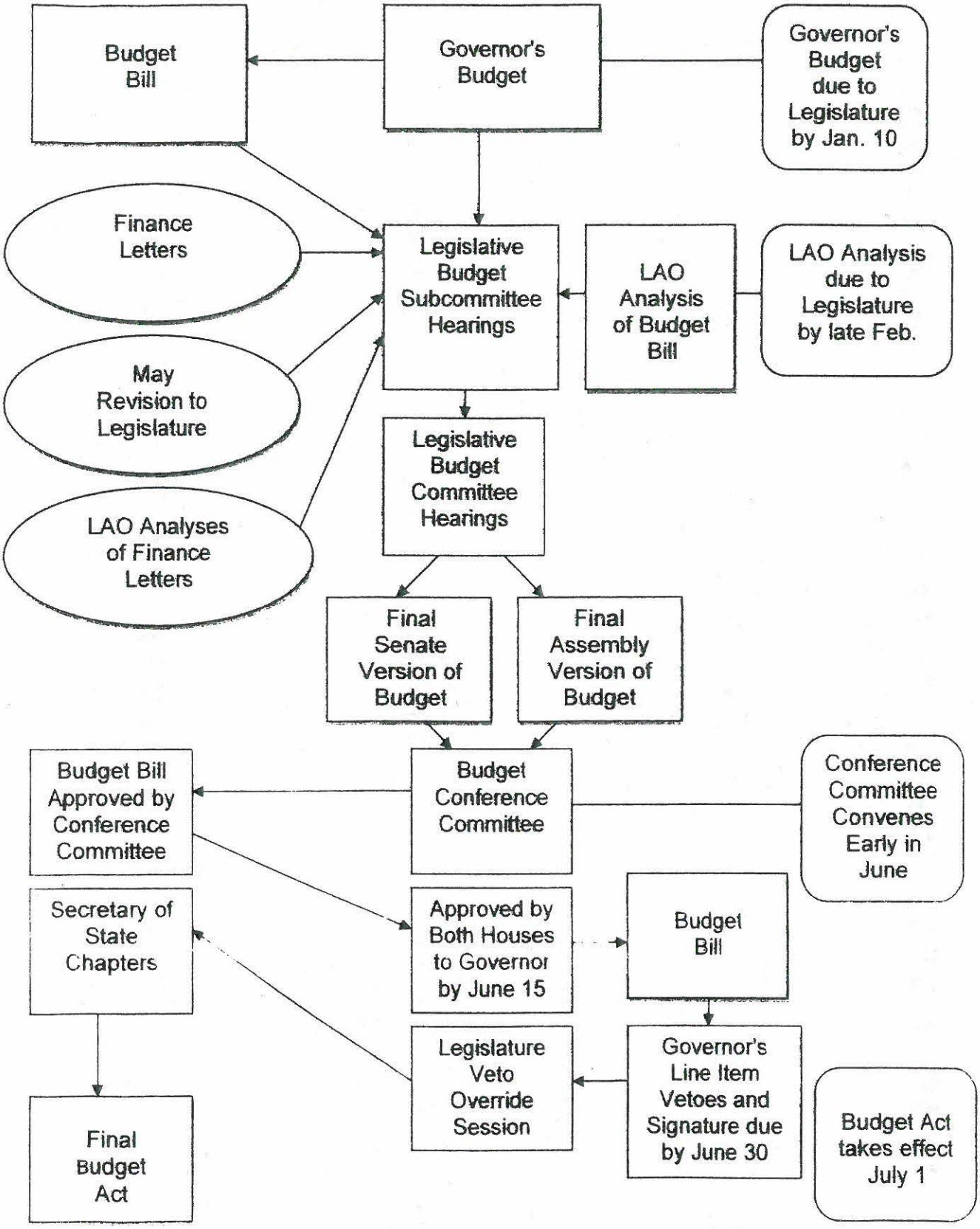
Typical committee actions are used to simplify charting the course of legislation.

Some bills require hearings by more than one committee, in which case a committee may re-refer the bill to another committee. For example, bills with monetary implications must be re-referred to the proper fiscal committee in each House before they are sent to the second reading file and final action.

A bill may be amended at various times as it moves through the Houses. The bill must be reprinted each time an amendment is adopted by either house. All bill actions are printed in the DAILY FILES, JOURNALS and HISTORIES.

If a bill is amended in the opposite House, it is returned to the House of Origin for concurrence in amendments. If House of Origin does not concur, a Conference Committee Report must then be adopted by each House before the bill can be sent to the Governor.

THE LEGISLATIVE BUDGET CYCLE



Family/Guardian Survey

Opinions of Services and Supports
for Adults with Intellectual/Developmental Disabilities and their Families in California

Thank you for helping us by completing the attached questionnaire. Your opinions will help improve services and supports to people with intellectual/developmental disabilities and their families in your state. The results of this survey will also allow us to compare family satisfaction with similar information collected in other states.

INSTRUCTIONS:

Note: If there is more than one person receiving services in your family, please answer the questions about the person who is named on the address label.

For most questions, all you need to do is check the box that applies to you. All responses will remain confidential (meaning your family member's case manager, providers, support workers, etc. will NOT know how you responded to these questions). Your answers will not affect the specific services and supports your family member is receiving. If you come to a question that you feel uncomfortable answering, skip it. However, for us to get complete information, it is very important that you try to answer each question as accurately as you can.

When you have completed the questionnaire:

Please return it to us in the enclosed pre-addressed and pre-stamped envelope. Please try to return the survey as soon as possible.

If you would like to receive help reading or understanding this survey, or if you need an interpreter, please call: **David Grady at (408) 324-2106**

Again, Thank You!

Part 1: INFORMATION ABOUT YOUR FAMILY

Please answer the following questions about your family member with a disability.

a.) Does this person live at home with you?

❑ 1. Yes ❑ 2. No

Note: If you answered "yes" to the question above, please stop here and return the survey.

b.) Where does this person live?

❑ 1. Specialized facility for persons with an Intellectual Disability (mental retardation)
❑ 2. Group home
❑ 3. Agency-owned apartment
❑ 4. Independent home or apartment
❑ 5. Adult foster care/host family home
❑ 6. Nursing home
❑ 7. Other

c.) How old is your family member with a disability? _____ years

d.) What is the gender of this person?

❑ 1. Male ❑ 2. Female

e.) Has this person been diagnosed with any disabilities listed below? (check all that apply)

❑ 1. Intellectual disability (mental retardation)
❑ 2. Mental illness/Psychiatric diagnosis (e.g. depression)
❑ 3. Autism spectrum disorder (e.g., autism, asperger syndrome, pervasive developmental disorder)
❑ 4. Cerebral palsy
❑ 5. Brain injury
❑ 6. Seizure disorder/Neurological problem
❑ 7. Chemical dependency
❑ 8. Limited or No Vision- Legally Blind
❑ 9. Hearing loss- Severe or Profound
❑ 10. Physical disabilities
❑ 11. Communication disorder
❑ 12. Alzheimer's disease or other dementia
❑ 13. Down syndrome

- ❑ 14. Prader-Willi syndrome
- ❑ 15. Other disabilities not listed
- ❑ 16. Don't know

f.) What is this person's race? (check all that apply)

- ❑ 1. American Indian or Alaska Native
- ❑ 2. Asian
- ❑ 3. Black or African-American
- ❑ 4. Native Hawaiian or Other Pacific Islander
- ❑ 5. White
- ❑ 6. Other/Unknown
- ❑ 7. Mixed (Two or More Races)
- ❑ 8. Hispanic or Latino

g.) What is your family member's primary means of expression?

- ❑ 1. Spoken
- ❑ 2. Gestures/Body Language
- ❑ 3. Sign Language/Finger Spelling
- ❑ 4. Communication Aid/Device
- ❑ 5. Other

h.) What is this person's primary language?

❑ 1. English ❑ 2. Spanish ❑ 3. Other

i.) What is this person's highest education level?

- ❑ 1. Less than High School Diploma/GED
- ❑ 2. High School Diploma/GED
- ❑ 3. Vocational School
- ❑ 4. Some College
- ❑ 5. College Degree

j.) What does this person typically do during the day? CHECK ALL THAT APPLY

- ❑ 1. Out of Home Day Program- unpaid
- ❑ 2. Out of Home Day Program- paid
- ❑ 3. Vocational Training
- ❑ 4. Community Employment- unpaid (e.g., volunteer work)
- ❑ 5. Community Employment- paid
- ❑ 6. In-home Day Supports
- ❑ 7. At home- by choice
- ❑ 8. At home- no services
- ❑ 9. At home- other
- ❑ 10. Other

k.) How often does this person require medical care by a trained medical provider (e.g., nurse or physician)?

- ❑ 1. Less frequently than once/month
- ❑ 2. At least once/month, but not once/week
- ❑ 3. At least once/week, or more frequently

l.) Does this person need support to manage any of the following behaviors: self-injurious behavior, disruptive behavior, destructive behavior?

- ❑ 1. No support needed
- ❑ 2. Some support needed
- ❑ 3. Extensive support needed

m.) About how much help does your family member need with daily activities (such as bathing, dressing, eating)? (check one)

- ❑ 1. None
- ❑ 2. Little
- ❑ 3. Moderate
- ❑ 4. Complete

Please answer the following questions about yourself.

n.) What is <u>your</u> age?

- ❑ 1. Under 35
- ❑ 2. 35 - 54
- ❑ 3. 55 - 74
- ❑ 4. 75 or Older

o.) How are you related to this person?

- ❑ 1. Parent (biological, adoptive, or foster)
- ❑ 2. Sibling
- ❑ 3. Spouse
- ❑ 4. Other (please describe)_____

p.) Are you a legal guardian (e.g., you have been appointed by the court) or conservator for this person?

- ❑ 1. Yes, full guardianship/conservatorship
- ❑ 2. Yes, limited guardianship/conservatorship
- ❑ 3. No

q.) Typically, how often do you see this person each year? (check one)

- ❑ 1. Less than once
- ❑ 2. 1 to 3 times
- ❑ 3. 4 to 6 times
- ❑ 4. 7 to 12 times
- ❑ 5. More than 12 times

r.) What is <u>your</u> highest education level?

- ❑ 1. Less than High School Diploma/GED
- ❑ 2. High School Diploma/GED
- ❑ 3. Vocational School
- ❑ 4. Some College
- ❑ 5. College Degree

s.) What was the total taxable income last year of the wage earner(s) in your household? (check one)

- ❑ 1. Below $15,000
- ❑ 2. $15,001- $25,000
- ❑ 3. $25,001- $50,000
- ❑ 4. $50,001- $75,000
- ❑ 5. Over $75,000

t.) Approximately how much out-of-pocket money did you spend last year on your family member's medical services, equipment, supplies, therapies, and other supports/services?

- ❑ 1. Nothing
- ❑ 2. $1- $100
- ❑ 3. $101- $1,000
- ❑ 4. $1,001- $10,000
- ❑ 5. Over $10,000

u.) What County do you currently live in?

_____

SERVICES AND SUPPORTS RECEIVED

Please check whether your family member with an intellectual/developmental disability is currently receiving any of the services or supports from the regional center described below.

		YES	NO	DON'T KNOW
i.	**Residential Supports** -- your family member with an intellectual/ developmental disability receives care and support in a residence outside of your home.	❑ 1	❑ 2	❑ 3
ii.	**Day/Employment Supports** – your family member with an intellectual/developmental disability attends a day program, workshop, or receives vocational supports such as job training or job coaching at a job in the community.	❑ 1	❑ 2	❑ 3
iii.	**Transportation** – someone arranges or provides for transportation for your family member with an intellectual/developmental disability to go to a day program, work, medical appointments, etc.	❑ 1	❑ 2	❑ 3
iv.	**Other Services/Supports** – your family member with a disability receives mental/behavioral health care and/or other treatments or therapies (such as physical therapy, occupational therapy, speech, or recreational therapy).	❑ 1	❑ 2	❑ 3

Additional Services Question (non ID/DD Agency Services):

Social Security Benefits -- your family/family member receives SSI payments, survivor benefits, etc.	❑ 1	❑ 2	❑ 3

Part 2: QUESTIONS ABOUT SERVICES AND SUPPORTS

Please answer the following questions about services and supports provided to your family member by the regional center. Check one response for each question. If a question does not apply, please check the last column.

	INFORMATION & PLANNING	Always	Usually	Sometimes	Seldom	Never	Don't Know	N/A
1.	Do you get enough information to help you participate in planning services for your family member?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
2.	Is the information you receive easy to understand?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
3.	Is the case manager/service coordinator who assists your family member with planning generally respectful and courteous?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
4.	Is the case manager/service coordinator who assists your family member with planning generally knowledgeable?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
5.	Are you generally kept informed about how your family member is doing?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

	INFORMATION & PLANNING	Yes	No	Don't Know	N/A
6.	If your family member has a service plan, did **s/he** help develop the plan?	❑1	❑5	❑6	❑7
7.	If your family member has a service plan, did **you or another family member** help develop the plan?	❑1	❑5	❑6	❑7
8.	If your family member has a service plan, does the plan include services and supports that are important to him/her?	❑1	❑5	❑6	❑7

	INFORMATION & PLANNING (CONTINUED)	Yes	No	Don't Know	N/A
9.	Does the service plan include all the services and supports your family member needs?	❑1	❑5	❑6	❑7
10.	If your family member has a service plan, did you discuss how to handle emergencies related to your family member at the last service planning meeting?	❑1	❑5	❑6	❑7
11.	Have you or your family member received information about your family member's rights?	❑1	❑5	❑6	❑7

Additional Comments on Information and Planning

What are you most satisfied with? (Please write your answer below)

_____

What do you feel needs the most improvement? (Please write your answer below)

_____

	ACCESS & DELIVERY OF SUPPORTS	Always	Usually	Sometimes	Seldom	Never	Don't Know	N/A
12.	Are you able to contact your family member's support workers when you need to?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
13.	Are you able to contact your family member's case manager/service coordinator when you need to?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
14.	Does your family member receive all of the services listed in the service plan?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

ACCESS & DELIVERY OF SUPPORTS (CONTINUED)		Always	Usually	Sometimes	Seldom	Never	Don't Know	N/A
15.	Are service and supports available within a reasonable distance from your family member's home?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
16.	Do the services and supports change when your family member's needs change?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
17.	If your family member does not speak English or uses a different way to communicate (for example, sign language), are there enough support workers available who can communicate with him/her?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
18.	If English is your family member's first language, do the support workers communicate with him/her effectively in his/her primary language?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
19.	Are services delivered to your family member in a manner that is respectful to your family member's culture(s)?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
20.	Does your family member have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
21.	Do you feel there is consistency with the support workers who provide services to your family member?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
22.	Do the support workers have the right training to meet your family member's needs?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

	ACCESS & DELIVERY OF SUPPORTS (CONTINUED)	Always	Usually	Sometimes	Seldom	Never	Don't Know	N/A
23.	Do you feel that your family member's residential setting is a healthy and safe environment?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
24.	Do you feel that your family member's day/ employment setting is a healthy and safe environment?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

	ACCESS & DELIVERY OF SUPPORTS	Yes	No	Don't Know	N/A
25.	If your family member transitioned from school services to State funded services during the past year, were you happy with the transition process?	❑1	❑5	❑6	❑7

Additional Comments on Access and Delivery of Supports

What are you most satisfied with? (Please write your answer below)

_____

What do you feel needs the most improvement? (Please write your answer below)

_____

CHOICE & CONTROL		Always	Usually	Sometimes	Seldom	Never	Don't Know	N/A
26.	Does the agency providing residential services to your family member involve your family member in important decisions?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
27.	Does your family member choose the agencies or provider organizations that support him or her?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
28.	If your family member at least sometimes chooses the agencies or provider organizations, does s/he have more than one agency/provider organization to choose from?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
29.	Does your family member choose the individual support workers who work directly with him/her?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
30.	If your family member at least sometimes chooses the support workers, is s/he satisfied with the options available?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

CHOICE & CONTROL		Yes	No	Don't Know	N/A
31.	Did your family member choose his/her case manager/service coordinator?	❑1	❑5	❑6	❑7
32.	Does your family member have control and/or input over the hiring and management of his/her support workers?	❑1	❑5	❑6	❑7
33.	Does your family member <u>want</u> to have control and/or input over the hiring and management of his/her support workers?	❑1	❑5	❑6	❑7

CHOICE & CONTROL (CONTINUED)		Yes	No	Don't Know	N/A
34.	Does your family member know how much money is spent by the regional center on his/her behalf?	❑1	❑5	❑6	❑7
35.	Does your family member have a say in how this money is spent?	❑1	❑5	❑6	❑7
36.	If "yes" (to Q35), does your family member have all the information s/he needs to make decisions about how to spend this money?	❑1	❑5	❑6	❑7

Additional Comments on Choice and Control

What are you most satisfied with? (Please write your answer below)

_____

What do you feel needs the most improvement? (Please write your answer below)

_____

COMMUNITY CONNECTIONS		Always	Usually	Sometimes	Seldom	Never	Don't Know	N/A
37.	If your family member wants to use typical supports in your community (for example, through recreation departments or churches), do either the case manager/service coordinator who helps plan or the support workers who provide support help connect him/her to these supports?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

COMMUNITY CONNECTIONS (CONTINUED)		Always	Usually	Sometimes	Seldom	Never	Don't Know	N/A
38.	If your family member would like to use family, friends, or neighbors to provide some of the supports s/he needs, do either the case manager/service coordinator who helps plan or the support workers who provide support help him/her do this?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

COMMUNITY CONNECTIONS		Yes	No	Don't Know	N/A
39.	Does your family member participate in community activities?	❑1	❑5	❑6	❑7
39 a.	If "no" (to Q39), why has your family member been unable to participate in community activities? (indicate here)				
40.	Does your family member have friends or relationships with persons other than paid staff or other family members?	❑1	❑5	❑6	❑7
41.	Does your family member have enough support (e.g., support workers, community resources) to work or volunteer in the community?	❑1	❑5	❑6	❑7

Additional Comments on Community Connections

What are you most satisfied with? (Please write your answer below)

_____

What do you feel needs the most improvement? (Please write your answer below)

_____

SATISFACTION		Always	Usually	Sometimes	Seldom	Never	Don't Know	N/A
42.	Overall, are you satisfied with the services and supports your family member currently receives?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

SATISFACTION		Yes	No	Don't Know	N/A
43.	Are you familiar with the process for filing a complaint or grievance regarding problems with your family member's provider agency/agencies or staff that provide services?	❑1	❑5	❑6	❑7
44.	Are you satisfied with the way complaints/grievances regarding provider agencies or staff are handled and resolved?	❑1	❑5	❑6	❑7
45.	Do you know how to report abuse and neglect?	❑1	❑5	❑6	❑7
46.	In the past year, did you report abuse and neglect?	❑1	❑5	❑6	❑7
47.	If "yes" (to Q46), were the appropriate parties responsive to your report?	❑1	❑5	❑6	❑7

Additional Comments on Satisfaction

What are you most satisfied with regarding service and supports? (Please write your answer below)

_____

What do you feel needs the most improvement regarding services and supports? (Please write your answer below)

_____

	OUTCOMES	Yes	No	Don't Know	N/A
48.	Do you feel that services and supports have made a positive difference in the life of your family member?	❑1	❑5	❑6	❑7
49.	Do you feel that services and supports have reduced your family's out-of-pocket expenses related to your family member's care?	❑1	❑5	❑6	❑7
50.	Do you feel that the services and supports received address the goals outlined in your family member's service plan?	❑1	❑5	❑6	❑7
51.	Overall, do you feel that your family member has a good quality of life?	❑1	❑5	❑6	❑7
52.	Have the services or supports that your family member has received during the past year been either reduced, suspended, or terminated?	❑1	❑5	❑6	❑7
53.	If "yes" (to Q52), did the reduction/suspension/termination of these services or supports affect your family member's home, job, relationships, etc.?	❑1	❑5	❑6	❑7

Is there anything else you would like to discuss? (Please write your answer below)

_____

Family Survey Feedback Sheet

Please help us improve this survey by answering the questions below:

1. How long did it take you to complete this survey?

_____ hour(s) _____minutes

2. Were there any questions that were difficult to understand? If yes, please list below:

Question#	Reason
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

3. Any other comments regarding this survey:

_____

_____

_____

_____

_____

_____

_____

Section 8. Behavior Analyst Certification Board (BACB)

GUIDELINES

Health Plan Coverage of Applied Behavior Analysis Treatment for Autism Spectrum Disorder

These standards are provided for informational purposes only, and do not represent professional or legal advice. There are many variables that influence and direct the professional delivery of ABA services. The BACB and authors of these standards assume no liability or responsibility for application of these standards in the delivery of ABA services. The standards presented in this document reflect the consensus of a number of subject matter experts, but do not represent the only acceptable practice. These standards also do not reflect or create any affiliation among those who participated in their development. The BACB does not warrant or guarantee that these standards will apply or should be applied in all settings. Instead, these standards are offered as an informational resource that should be considered in consultation with parents, behavior analysts, regulators, and third-party payers.

TABLE OF CONTENTS

PART I: Overview

PART II: Unique Features of Applied Behavior Analysis

PART III: Appendices

PART I: Overview

SECTION 1: EXECUTIVE SUMMARY

The purpose of this document is to inform decision-making regarding the use of Applied Behavior Analysis (ABA) to treat medically necessary conditions so as to develop, maintain, or restore, to the maximum extent practicable, the functioning of individuals with Autism Spectrum Disorder (ASD) in ways that are both efficacious and cost effective.[1]

The document is based on the best available scientific evidence and expert clinical opinion regarding the use of ABA as a behavioral health treatment for individuals diagnosed with ASD. The guidelines are intended to be a brief and user-friendly introduction to the application of behavior analysis for ASD when funded by health care plans. Although the guidelines are written primarily for insurers and health plans, they will also be useful for consumers and providers.

This document provides clinical guidelines and other information about ABA as a treatment for ASD. ABA has a number of clinical and delivery components that make it unique among evidence-based behavioral health treatments. Thus, it is important that those charged with building a provider network understand the components and delivery of ABA, including:

- training and credentialing of Behavior Analysts
- ABA as a treatment for ASD
  - treatment components
  - assessment, formulation of treatment goals, and measurement of client progress
  - clinical procedures
  - treatment dosage and duration
  - supervision model
  - tiered service delivery
  - involvement of caregivers and other professionals
  - discharge, transition planning, and continuity of care
- service authorization and benefit management

This is the first edition of this resource manual and it will be updated periodically to reflect changes in clinical practice and research findings. Additional references and information can be found in the appendices.

SECTION 2:
AUTISM SPECTRUM DISORDER AND APPLIED BEHAVIOR ANALYSIS

1 What is ASD?

ASD is characterized by varying degrees of difficulty in social interaction and verbal and nonverbal communication, and the presence of repetitive behavior and restricted interests.[2] This means that no two individuals with an ASD diagnosis are the same with respect to how the disorder manifests. However, the severity of the disorder is a reality for all individuals with this diagnosis and their families. Because of the nature of the disability, people with ASD will often not achieve the ability to function independently without appropriate medically necessary treatment.

2 What is ABA?

ABA is the design, implementation, and evaluation of environmental modifications to produce socially significant improvement in human behavior. ABA includes the use of direct observation, measurement, and functional analysis of the relations between environment and behavior. ABA uses changes in environmental events, including antecedent stimuli and consequences, to produce practical and significant changes in behavior. These relevant environmental events are usually identified through a variety of specialized assessment methods. ABA is based on the fact that an individual's behavior is determined by past and current environmental events in conjunction with organic variables such as their genetic endowment and ongoing physiological variables. ABA focuses on treating behavioral difficulties by changing the individual's environment rather than focusing on variables that are, at least presently, beyond our direct access.

The successful remediation of core deficits of ASD, and the development or restoration of abilities, documented in hundreds of peer-reviewed studies published over the past 50 years has made ABA the standard of care for the treatment of ASD.

SECTION 3:
CONSIDERATIONS

- This document contains guidelines and recommendations that reflect established research findings and best clinical practices. However, individualized treatment is a defining feature and integral component of ABA, which is one reason why it has been so successful in treating this heterogeneous disorder.

- Some individuals diagnosed with ASD have co-occurring conditions including, but not limited to intellectual disabilities, seizure disorders, psychiatric disorders, chromosomal abnormalities, feeding disorders, and a variety of other conditions that require additional medical treatment. **These guidelines apply to individuals diagnosed with ASD with these co-occurring conditions, as research has established ABA as effective for these client populations as well.**

- The guidelines provided in this document are pertinent to developing, maintaining, or restoring, to the maximum extent practicable, the functioning of an individual with ASD and thus, may not necessarily represent the optimal guidelines for producing an "appropriate education" in school settings.

- These guidelines should not be used to diminish the availability, quality, or frequency of currently available ABA treatment services.

- Coverage of ABA treatment for ASD by a health plan does not supplant responsibilities of educational or governmental entities.

- Specification of ABA in an Individualized Educational Plan or government program does not supplant ABA coverage by a health plan.

- ABA treatment must **not** be restricted *a priori* to specific settings but instead should be delivered in those settings that maximize treatment outcomes for the individual client.

- This document provides guidance regarding ABA treatment only; other behavioral health treatments are not addressed.

- In addition to ASD, ABA as a behavioral health treatment has a profound impact on the treatment of individuals with a range of clinical needs such as smoking cessation, severe problem behavior (e.g., self injury), weight loss, attention deficit disorder, pediatric feeding/eating disorders, and rehabilitation of acute medical conditions. Elements of this report may be applicable to the treatment of these other conditions as well, but this document is specifically directed towards the use of ABA in the treatment of ASD.

PART II:
Unique Features of Applied Behavior Analysis

SECTION 1:
TRAINING AND CREDENTIALING OF BEHAVIOR ANALYSTS

ABA is a specialized behavioral health treatment and most graduate or postgraduate training programs in psychology, counseling, social work, or other areas of clinical practice do not provide in-depth training in this discipline. Thus, an understanding of the credentialing process of Behavior Analysts by the Behavior Analyst Certification Board® (BACB®) can assist health plans and their subscribers in identifying those providers who meet the basic competencies to practice ABA.

The formal training of professionals certified by the BACB is similar to that of other medical and behavioral health professionals. That is, they are initially trained within academia and then begin working in a supervised clinical setting with clients. As they gradually demonstrate the competencies necessary to manage complex clinical problems across a variety of clients and medical environments, they become independent practitioners. In summary, Behavior Analysts undergo a rigorous course of training and education and have an "internship" period in which they begin by working under the direct supervision of an experienced Behavior Analyst.

It should be noted that other licensed professionals may have ABA within their particular scope of training and competence. In addition, a small subset of clinicians may be licensed by another profession and also hold a credential from the BACB, thereby providing evidence of the nature and depth of their training in ABA.

While health plan coverage of behavioral health treatments supervised by Behavior Analysts is relatively recent, Behavior Analysts, like other medical and behavioral health providers, rely upon strategies and procedures documented in peer-reviewed literature, established treatment protocols, and decision trees. They continually evaluate the current state of the client and customize treatment options based on the results of direct observation and data from a range of other assessments. They also solicit and integrate information from the client and family members and coordinate care with other professionals.

The Behavior Analyst Certification Board

The BACB is a nonprofit 501(c)(3) corporation established to meet professional credentialing needs identified by Behavior Analysts, governments, and consumers of behavior analysis services. The mission of the BACB is to develop, promote, and implement an international certification program for Behavior Analyst practitioners. The BACB has established uniform content, standards, and criteria for the credentialing process that are designed to meet:

- The legal standards established through state, federal, and case law;
- The accepted standards for national certification programs; and
- The "best practice" and ethical standards of the behavior analysis profession.

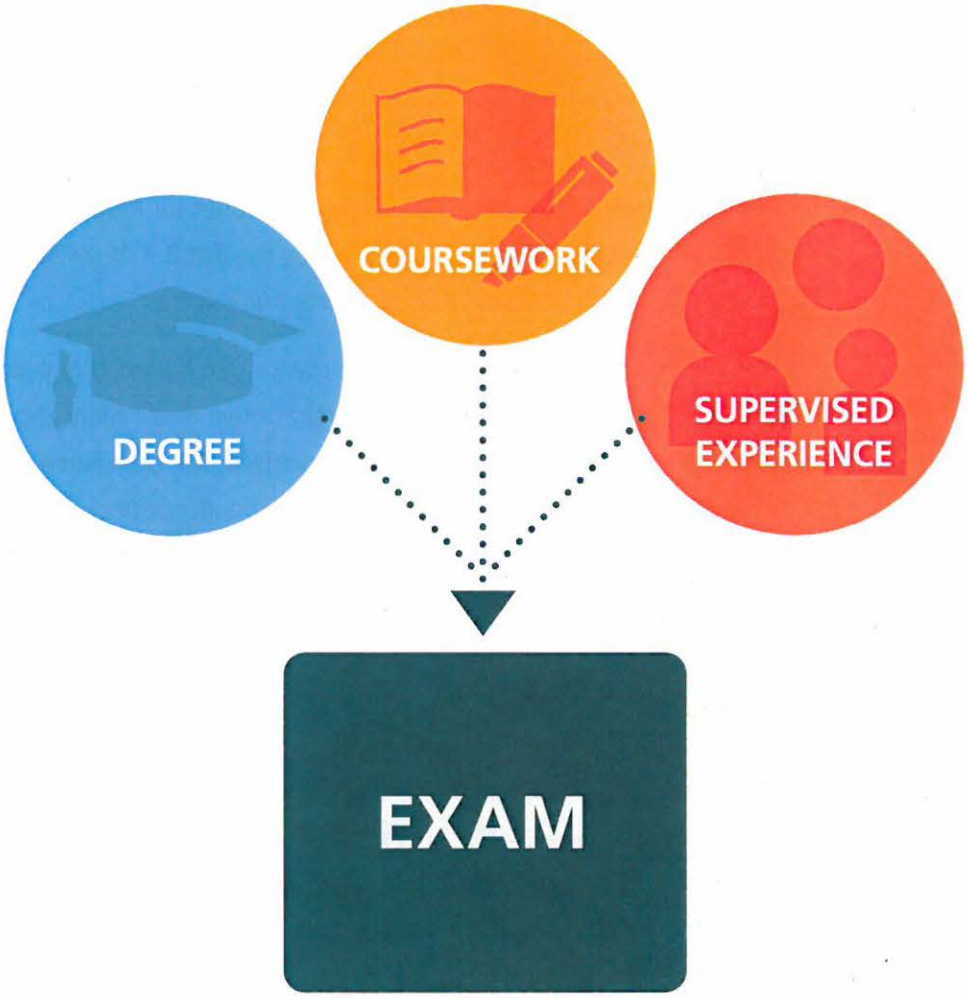
The BCBA and BCaBA certification programs are currently accredited by the National Commission for Certifying Agencies (NCCA), the accreditation arm of the Institute for Credentialing Excellence. NCCA reviews and oversees all aspects related to ensuring the development and application of appropriate credentialing processes.

The BACB credentials and recognizes practitioners at three levels:

Professionals credentialed at the BCBA-D and BCBA levels are defined as Behavior Analysts. The BACB requires that BCaBAs work under the supervision of a BCBA-D or BCBA.

Eligibility Requirements

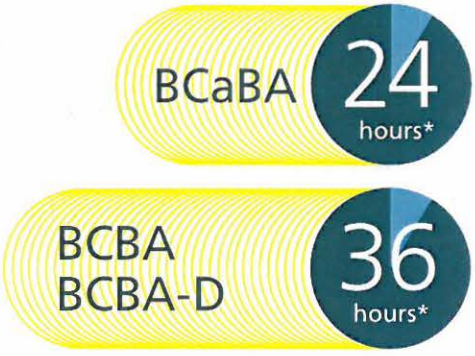
Applicants who meet the degree, coursework, and supervised experience eligibility requirements described in the next section are permitted to sit for either the BCBA or BCaBA examination (see figure below). Each examination is professionally developed to meet accepted examination standards and is based on the results of a formal job analysis and survey. In addition, all BACB examinations are offered under secure testing conditions and are professionally administered and scored by independent professional entities that meet industry standards.



Primary requirements for certification by the BACB.

Continuing Education and Maintaining Certification

BACB certificants are required to attest to their compliance with the organization's ethical and disciplinary rules (see below) on an annual basis and obtain 24 (BCaBA) or 36 (BCBA, BCBA-D) hours of continuing education credits every three years, three hours of which must relate to ethics or professionalism. Agencies that employ Behavior Analysts need to support and provide this training as needed.



*continuing ed. credits every 3 years

Disciplinary Procedures

All certificants must annually attest that they will follow the Guidelines for Responsible Conduct for Behavior Analysts and they are subject to disciplinary action by the BACB if they violate one or more of the nine Professional Disciplinary and Ethical Standards (www.BACB.com).

The BACB uses an online complaint system by which the organization is alerted to potential disciplinary violations. Each complaint is evaluated by the BACB legal department and if there appears to be merit to the complaint it is forwarded to a disciplinary Review Committee. The committee members are senior BCBAs or BCBA-Ds selected for their knowledge and independence (including a member from the certificant's state). Disciplinary actions for certificants include, but are not limited to, mandated continuing education, suspension of certification, or revocation of certification. Resulting disciplinary actions are publicly reported online.

Licensure of Behavior Analysts

BACB credentials are currently the basis for licensure in those states where Behavior Analysts are licensed. Basing licensure on BACB credentials is cost effective and ensures that critical competencies with regards to practice and research are periodically reviewed and updated by practitioners and researchers. Whether it is used as the basis for licensure or as a "free standing" credential, BACB credentials are recognized in those states where insurance reform laws have been enacted.

SECTION 2:

APPLIED BEHAVIOR ANALYSIS IN THE TREATMENT OF ASD

The field of Behavior Analysis evolved from the scientific study of the principles of learning and behavior. Applied Behavior Analysis is a well-developed discipline among the helping professions, with a mature body of scientific knowledge, established standards for evidence-based practice, distinct methods of service, recognized experience and educational requirements for practice, and identified sources of requisite education in universities. Professionals in ABA engage in the specific and comprehensive use of principles of learning, including operant and respondent learning, in order to address behavioral needs of widely varying individuals in diverse settings.

1 Identifying ABA Treatment

Health plans and insurers must be able to recognize bona fide ABA treatment and those qualified to provide it. ABA treatment has some important characteristics that should be apparent throughout treatment:

1. An objective analysis of the client's condition by observing how the environment affects the client's behavior, as evidenced through appropriate data collection
2. Importance given to understanding the context of the behavior and the behavior's value to the individual and the community
3. Utilization of the principles and procedures of behavior analysis such that the client's health, independence, and quality of life are improved

2 Essential Practice Elements of ABA

These characteristics should be apparent throughout all phases of assessment and treatment:

1. **Description of specific levels of behavior at baseline** when establishing treatment goals
2. A practical focus on **establishing small units of behavior** which build towards larger, more significant changes in functioning related to improved health and levels of independence
3. Collection, quantification, and analysis, of **direct observational data** on behavioral targets during treatment and follow-up to maximize and maintain progress towards treatment goals
4. An emphasis on **understanding the current function** and future value (or importance) of behavior(s) targeted for treatment
5. Efforts to design, establish, and **manage the treatment environment(s)** in order to minimize problem behavior(s) and maximize rate of improvement
6. Use of a **carefully constructed, individualized and detailed behavior analytic treatment plan** which utilizes reinforcement and other behavior analytic principles as opposed to the use of methods or techniques which lack consensus about their effectiveness based on evidence in peer-reviewed publications
7. An emphasis on **ongoing and frequent direct assessment, analysis, and adjustments to the treatment plan** (by the Behavior Analyst) based on client progress as determined by observations and objective data analysis
8. Use of **treatment protocols that are implemented repeatedly, frequently, and consistently** across environments until the client can function independently in multiple situations
9. **Direct support and training of family members and other involved professionals** to promote optimal functioning and promote generalization and maintenance of behavioral improvements
10. **Supervision and management by a Behavior Analyst** with expertise and formal training in ABA for the treatment of ASD

3 Treatment Models

ABA treatment programs for ASD incorporate findings from hundreds of applied studies focused on understanding and treating ASD published in peer-reviewed journals over a 50-year span. Treatment may vary in terms of intensity and duration, the complexity and range of treatment goals, and the extent of direct treatment provided. Many variables, including the number of behavioral targets, specific aspects of those behaviors, and the client's own response to treatment help determine which model is most appropriate. Although existing on a continuum, these differences can be generally categorized as one of two treatment models: Focused ABA or Comprehensive ABA.[3]

Focused ABA

Service Description

Focused ABA involves direct service delivery to the client. It is not restricted by age, cognitive level, or co-occurring conditions. Focused ABA refers to treatment provided directly to the client for a limited number of behavioral targets.

Focused ABA involves direct service delivery to the client. It is not restricted by age, cognitive level, or co-occurring conditions.

Although the presence of problem behaviors may more frequently trigger a referral for Focused ABA treatment, the absence of appropriate behaviors should be prioritized, as this is often the precursor to serious behavior problems. Therefore, individuals who need to acquire skills (e.g., communication, tolerating change in environments and activities, self-help, social skills) are also appropriate for Focused ABA. In addition, all treatment plans which target reduction of dangerous or undesired behavior must concurrently introduce and strengthen more appropriate and functional behavior.

Examples of behavior-change targets in a focused ABA treatment plan for children who lack key functional skills include establishing compliance with medical and dental procedures, sleep hygiene, self-care skills, safe and independent leisure skills (e.g., appropriate participation in family and community activities).

Examples of treatment targets where the primary goal is to reduce behavior problems might include, but are not limited to, physical or verbal aggression towards self or others, dysfunctional speech, stereotypic motor behavior, property destruction, noncompliance and disruptive behavior, or dysfunctional social behavior.

When prioritizing the order in which to address multiple treatment targets, the following should be considered:

- **behaviors that may threaten the health or safety of themselves or others** (e.g., aggression, self-injury or self-mutilation, property destruction);
- **behavior disorders that may be a barrier to their ability to remain in the least restrictive setting, and/or limit their ability to participate in family and community life** (e.g., aggression, self-injury, noncompliance);
- **absence of developmentally appropriate adaptive, social, or functional skills** (e.g., toileting, dressing, feeding, compliance with medical procedures) that are fundamental to maintain health, social inclusion, and increased independence.

When the focus of treatment involves the reduction of a problem behavior, the Behavior Analyst will determine which situations are most likely to precipitate problem behavior and begin to isolate its function or purpose. This may require conducting a functional analysis to empirically demonstrate the "purpose" (i.e., function) of the problem behavior. The results enable the Behavior Analyst to develop the most effective treatment protocol. When the function of the problem behavior is identified, the Behavior Analyst may design a treatment plan that alters the environment to reduce the motivation for problem behavior and/or establish a new and more appropriate behavior that serves the same function and therefore "replaces" the problem behavior.

Social skills deficits, a core deficit of individuals diagnosed with ASD, are often addressed in focused treatment programs. Treatment may be delivered in either an individual or small-group format. When conducted in a small group, typically developing peers, or others with similar diagnoses, participate in the session. Clients practice behavioral targets while simultaneously mediating delivery of the treatment to the other members of the group. As is the case for all treatments, programming for generalization of skills outside the session is critical.

Focused treatments generally range from 10-25 hours per week of direct therapy (plus direct and indirect supervision hours) and are sometimes part of a step down or discharge plan from a Comprehensive ABA Treatment program.

Comprehensive ABA Treatment

Service Description

Comprehensive ABA refers to treatment where there are multiple targets across all developmental domains that are affected by the individual's ASD. These programs tend to range from 26-40 hours of direct treatment plus supervision per week. Initially, this typically involves 1:1 staffing and may gradually include small group formats as is appropriate.

Although there are different examples of comprehensive treatment, one example is intensive early treatment where the overarching goal is to close the gap between the client's level of functioning and that of typically developing peers. Targets are drawn from multiple domains of functioning including cognitive, communicative, social, and emotional. Targets also include reducing the symptoms of co-occurring behavior disorders such as aggression, self-injury and stereotypy. However, comprehensive behavioral treatment may also be appropriate for older individuals diagnosed with ASD, particularly if they engage in severe or dangerous behaviors across environments. In some cases, residential placement or inpatient hospitalization may be required for a period of time.

Treatment hours are increased or decreased as a function of the client's response to treatment as well as the intensity needed to reach treatment goals. In some cases, direct treatment hours increase gradually, are maintained at maximum intensity for a period of time, and are then systematically decreased in preparation for discharge. In other cases, treatment may begin at maximum levels.

Treatment is intensive and initially provided in structured therapy sessions. More naturalistic treatment approaches are utilized as soon as the client demonstrates the ability to benefit from these treatments. As the client progresses and meets established criteria for participation in larger or different settings, treatment in those settings and in the larger community should be provided. Training and participation by caregivers are also seen as an important component.

Program Components

Treatment components should generally be drawn from the following domains:

- cognitive functioning
- pre-academic skills
- safety skills
- social skills
- play and leisure skills
- community integration
- vocational skills
- coping and tolerance skills
- adaptive and self-help skills
- language and communication
- attending and social referencing
- reduction of interfering or inappropriate behaviors

Intensity of Comprehensive ABA Treatment

When the goal is to change developmental trajectories to match that of typically developing peers, research, including several meta-analyses, show that 30–40 hours per week (6–7 hours daily, 5–6 days/week) of intensive ABA treatment is needed. Hours generally decrease as the client progresses in independence and generalizes behavioral changes to other critical settings.

Children who are under 3 years of age with an ASD diagnosis have better outcomes when they receive 25-30 hours/week, and it is not uncommon for children in this age group to receive 30 hours of treatment or more as they approach 3 years of age. Children who present characteristics of ASD at age 36 months will continue to require ongoing treatment.

Recommended hours and session lengths are based on the individual's characteristics, goals and availability for therapy (e.g., endurance, attention span, need for naps). Although the recommended number of hours of therapy may seem arduous to some parents of young children, it should be noted that time spent away from therapy may move children even farther away from desired normal developmental trajectories. Such delays will likely result in increased costs and greater dependence on more intensive services across their life span.

4 Variations Within These Models

Treatment programs within any of these models vary along several programmatic dimensions, including the degree to which they are primarily provider- or client-directed (sometimes described as "structured vs. naturalistic"). Other variations include the extent to which peers or parents serve as behavior change agents. Finally, some differ in terms of the degree to which they are "branded" and available commercially.

Decisions about how these various dimensions are implemented within individual treatment plans must reflect many variables, including the research base, the age of the client, specific aspects of the target behaviors, the client's own rate of progress, demonstration of prerequisite skills, and resources required to support implementation of the treatment plan across settings.

Despite such differences, if a given treatment meets the Essential Practice Elements of ABA described in this section (p.11), a treatment program should be considered an ABA treatment.

5 ABA Procedures Employed In These Models

A large number of ABA procedures are routinely employed within the models previously described. They differ from one another in their complexity, specificity, and the extent to which they were designed primarily for use with individuals diagnosed with ASD. All are based on the principles of ABA and are employed with flexibility determined by the individual's specific treatment plan and response to treatment. If one ABA procedure or combination of ABA procedures is not producing the desired response, a different one may be systematically implemented and evaluated for its effectiveness.

These procedures include different types of reinforcement and schedules of reinforcement, differential reinforcement of other behavior, differential reinforcement of alternative behavior, shaping, chaining, behavioral momentum, prompting and fading, behavioral skills training, functional communication training, discrete trial teaching, incidental teaching, self-management, preference assessments, activity schedules, generalization and maintenance procedures, among many others. The field of behavior analysis is constantly developing and evaluating applied behavior change procedures.

6 Locations Where Treatment is Delivered

The standard of care provides for treatment to be delivered in multiple settings in accordance with clinical judgment to promote generalization and maintenance of therapeutic benefits. No ABA model is specific to a particular location and all may be delivered in a variety of settings, including residential treatment facilities, clinics, homes, schools, and places in the community. Treatment provided in multiple settings, with multiple adults and/or siblings under the proper circumstances, will support generalization and maintenance of treatment gains. In some cases, the consistent application of ABA across all settings of the person's life may be the most cost-effective means of treatment.

Where possible, most children under 3 years of age should receive at least some treatment in their home. However, treatment should not be withheld, nor should family members be expected to forego employment, etc., in order to receive such treatment. Under certain circumstances, clinic-based services are most appropriate.

7 Client Age

Services should be provided as soon as possible after diagnosis, and in some cases services are warranted prior to diagnosis. Evidence suggests that the earlier treatment begins, the greater the likelihood of positive long-term outcomes. Comprehensive ABA treatment can result in reduced need for services as the child grows older. However, research also demonstrates that ABA is effective across the life span. Older individuals may also need intensive and comprehensive treatment, especially if they present with dangerous behaviors. Research has not established an age limit beyond which ABA is not effective.

Evidence suggests that the earlier treatment begins, the greater the likelihood of positive long-term outcomes.

8 Combining ABA With Other Forms Of Treatment

Findings from several studies show that an eclectic model, where ABA is combined with other forms of treatment, is less effective than ABA alone. Therefore, treatment plans which involve a mixture of methods, especially those which lack proven effectiveness, should be considered with caution and, if approved, should be monitored carefully. If there are treatment protocols that are not aligned with the ABA treatment approach, these differences must be resolved in order to deliver anticipated benefits to the client.

SECTION 3:
ASSESSMENT, FORMULATION OF TREATMENT GOALS, AND MEASUREMENT OF CLIENT PROGRESS

1 The Assessment Process

A developmentally appropriate ABA assessment plan must identify strengths and weaknesses across domains. The data from such a plan should be the basis for developing the individualized treatment plan. An ABA assessment typically utilizes data obtained from multiple methods and multiple informants, such as:

Direct observation and measurement of behavior

Direct observation, measurement, and recording of behavior is a defining characteristic of ABA. These data serve as the primary basis for identifying pre-treatment levels, discharge goals, and evaluation of response to an ABA treatment program. They also assist the Behavior Analyst in developing and adapting treatment protocols on an ongoing basis. Direct observation of behavior should happen during naturally occurring opportunities, as well as, structured interactions.

File review and administration of a variety of behavior scales or other assessments as appropriate

The types of assessments should reflect the goal of treatment and should be responsive to ongoing data as they are collected and analyzed.

Interviews with the client, caregivers, and other professionals

Caregivers and other stakeholders are included when selecting treatment goals, protocols, and evaluating progress as appropriate. Caregiver interviews, rating scales, and social validity measures should be used to assess the caregiver's perceptions of their child's skill deficits and behavioral excesses, and the extent to which these deficits and excesses impede the life of the individual and the family. The client should also participate in these processes as appropriate.

2 Selection and Measurement of Goals

- Selection of a target-behavior definition, method and frequency of measurement approach, and data presentation must be individualized to each situation, behavior, and available resources.
- Behavioral targets should be prioritized based on their risk to client safety, independence, and implications for the client's health and well-being.
- Both baseline performance and treatment goals should be developed for each critical domain and specified in terms that are observable and measurable so that there is agreement regarding the presence, absence, or degree of behavior change relative to treatment goals and discharge criteria.
- Treatment plans should specify objective and measurable treatment protocols. It should include the service setting(s), and level of service for the client.
- Data collection and analysis should occur frequently enough so as to permit changes to the treatment plan at a rate which maximizes progress. Data should be represented in numerical or graphical form.

3 Data From Standardized Assessments

These data may help inform issues related to selection and prioritization of treatment goals and determining the response to treatment.

- Standardized tests that assess performance in cognitive, communicative, social, adaptive, behavioral domains may be appropriate to establish pre-treatment levels of performance and inform decision-making during treatment planning. Scores on such assessments, however, should not be used to exclude individuals from receiving ABA treatment. For example, cognitive functioning is not an accurate or appropriate determiner of an individual's response to ABA treatment.

- Assessment batteries must be individualized so that they are appropriate for each client. For example, nonverbal assessments may provide a more accurate profile for a client with limited verbal abilities.
- Formal standardized assessments may also be appropriate in some cases for use on an annual basis as part of assessing progress in a Comprehensive ABA treatment program where the goal is to close performance gaps with typically developing peers. However, scores on such assessments should not be used as the sole basis to terminate ABA treatment for individual clients.

4 Problem Behavior Assessment

Problem behavior assessment may also be required when co-occurring behavior disorders (e.g., aggression, self-injury, property destruction, stereotypy) are present, to identify the likely reason(s) problem behavior(s) occur and the skills and strategies necessary to ameliorate them. This necessitates a functional assessment, which may or may not involve a functional analysis (i.e., manipulation of environmental events and record of changes in strength of target behavior) to determine the function of the behavior problem.

5 Complexity of Assessment

In most cases, the ABA assessment can be completed in 15-20 hours (including report writing). However, up to 40 hours may be required if the Behavior Analyst needs to conduct a functional analysis to determine the function of the problem behavior.

SECTION 4:
SERVICE AUTHORIZATION AND DOSAGE

1 Services Authorized

Authorization periods should not be for less than 6 months and may involve some or all of the following services. If there is a question as to the appropriateness or effectiveness of ABA for a particular client, a review of treatment data may be conducted more frequently (e.g., after 3 months of treatment).

1. Assessment
2. Treatment Plan Development
3. Direct Treatment
4. Supervision (direct and indirect)
5. Parent and Community Caregiver Training
6. Consultation to Ensure Continuity of Care
7. Discharge Planning

2 Treatment Dosage

Treatment dosage, which is often referenced in the treatment literature as "intensity," will vary with each client and should reflect the goals of treatment, specific client needs, and response to treatment. Treatment dosage should be considered in two distinct categories: intensity and duration.

Intensity

Intensity is typically measured in terms of number of hours per week of direct treatment. Intensity often reflects whether the treatment is comprehensive (across multiple domains) or focused (limited number of behavioral targets).

If the goal of treatment is to bring the client's functioning to levels typical for that chronological age or maximize independence in multiple areas (e.g., cognitive, social, adaptive)...

- Comprehensive ABA requires intensive treatment, defined as 26-40 hours per week of direct treatment with adjustments based on individual client needs and response to treatment.
  - Treatment hours are most commonly in the range of 26-30 hours per week for children under 3 years of age and 30-40 hours per week for children over 3 years of age.
  - Treatment hours do not include time spent with other professionals or family members specifically trained to extend and amplify the benefits of treatment.

When the goal is to address a limited number of areas such as decreasing dangerous behavior or improving social skills (i.e., Focused ABA)...

- Direct treatment hours will be related to the client's individual needs and learning history, the need to train direct-care staff, assessment time, and data analysis.

In addition to intensity being measured in terms of treatment hours per week, intensity may be further defined in terms of the number of client behaviors or responses per hour as arranged by the treatment protocol. These are sometimes referred to as trials. Higher rates of trials, programmed with consistent implementation, are often important to obtaining adequate progress. Thus, intensity of treatment must reflect other aspects in addition to the number of treatment hours per day, week, or month.

Duration

Treatment duration is effectively managed by evaluating the client's response to treatment. This evaluation can be conducted prior to the conclusion of an authorization period. Some individuals will continue to demonstrate medical necessity and require treatment for a substantial duration (e.g., over a period of years). For example, the benefits of Comprehensive ABA require treatment to be delivered over multiple years.

SECTION 5:

TIERED SERVICE DELIVERY MODELS AND BEHAVIORAL TECHNICIANS

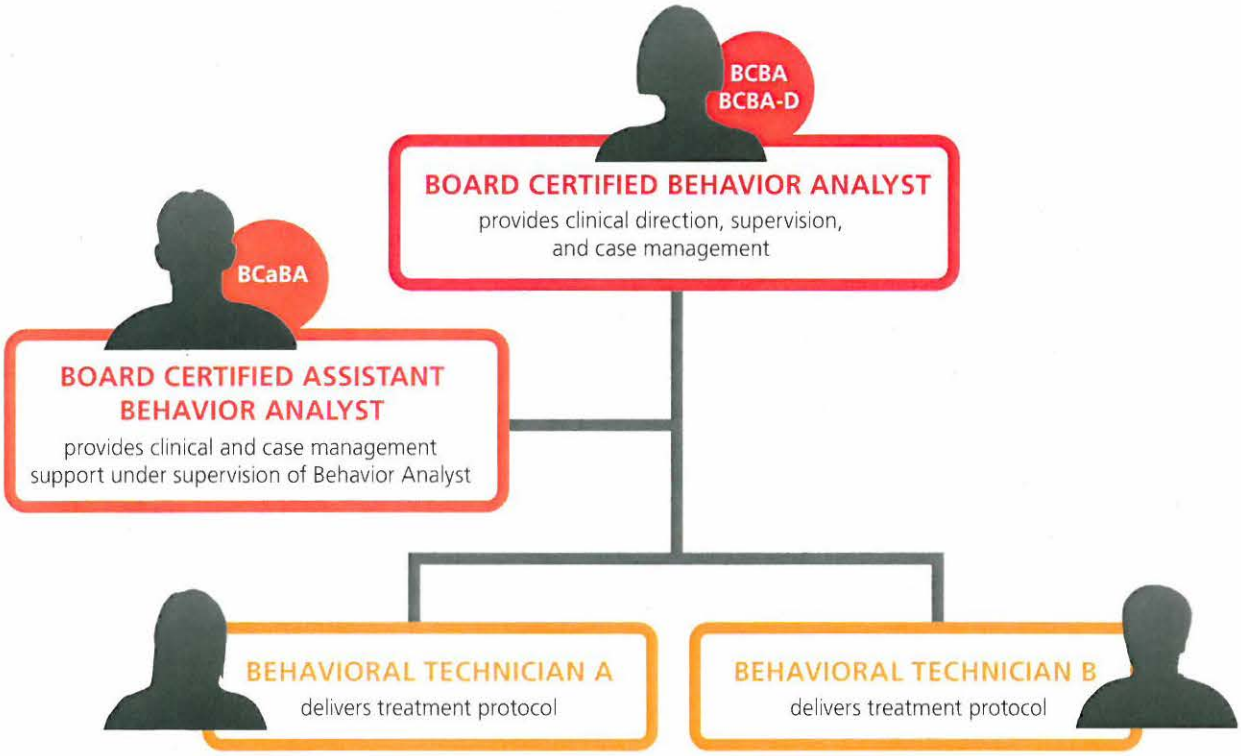
Most ABA treatment programs involve a tiered service delivery model where the Behavior Analyst designs and supervises a treatment program delivered by Behavioral Technicians.

1 Rationales for a Tiered Service Delivery Model

- Tiered service delivery models which rely upon the use of Behavioral Technicians have been the primary mechanism for achieving many of the significant improvements in cognitive, language, social, behavioral, and adaptive domains that have been documented in the peer-reviewed literature.[4]
- The use of carefully trained and well-supervised Behavioral Technicians is a common practice in ABA treatment.[5, 6]
- The use of Behavioral Technicians enables health plans and insurers ensure that they maintain adequate provider networks and deliver medically necessary treatment in a way that manages costs.
- The use of Behavioral Technicians produces more cost-effective levels of service for the duration of treatment because it allows the Behavior Analyst to manage more cases/hours of direct treatment.
- The use of the tiered service delivery model permits sufficient expertise to be delivered to each case at the level needed to reach treatment goals. This is critical as the level of supervision required may need to shift rapidly in response to rapid client progress or demonstrated need.
- Tiered service delivery models can help ensure that treatment is delivered to families in hard to access rural and urban areas as well as families who have complex needs.

The BCBA and BCBA-D's clinical, supervisory, and case management activities are often supported by other staff such as BCaBAs working within the scope of their training, practice, and competence.

Below is one example of this specific tiered service delivery model, an approach considered cost-effective at delivering desired treatment outcomes.



Such models assume the following:

1. The BCBA or BCBA-D is responsible for all aspects of clinical direction, supervision, and case management, including activities of the support staff (e.g., a BCaBA) and Behavioral Technicians.
2. The BCBA or BCBA-D must have knowledge of each person's ability to effectively carry out activities before assigning them.
3. The BCBA and BCBA-D provides case supervision, which must include direct, face-to-face supervision on a consistent basis, regardless of whether or not there is clinical support provided by a BCaBA.

2 Selection, Training, and Supervision of Behavioral Technicians

- Behavioral Technicians should meet specific criteria before providing treatment (refer to Sample Background Requirements on p. 27).

- Case assignment should match the needs of the client with the skill-level and experience of the Behavioral Technician. Before working with a client, the Behavioral Technician must be sufficiently prepared to deliver the treatment protocols. This includes a review by the Behavior Analyst of the client's history, current treatment programs, behavior reduction protocols, data collection procedures, etc.

- Caseloads for the Behavioral Technician are determined by the:
  - complexity of the cases
  - experience and skills of the Behavioral Technician
  - number of hours per week employed
  - intensity of hours of therapy the client is receiving

- Quality of implementation (treatment integrity checks) should be monitored on an ongoing basis. This should be more frequent for new staff, when a new client is assigned, or when a client has challenging behaviors or complex treatment protocols are involved.

- Behavioral Technicians should receive direction on the introduction and revision of treatment protocols on a weekly to monthly basis. This activity may be in client briefings with other members of the treatment team each month, including the supervising Behavior Analyst or individually, and with or without the client present. The frequency and format should be dictated by an analysis of the treatment needs of the client to make optimal progress.

- While hiring qualifications and initial training are important, there must be ongoing observation, training, and supervision to maintain and improve the Behavioral Technician's skills while implementing ABA-based treatment.

Sample Training and Job Requirements for Behavioral Technicians:

Background Requirements[7]

- ❑ High school graduate (minimum)
- ❑ AA degree (preferred)
- ❑ Pass criminal background check
- ❑ Pass TB test

Initial Training[8]

- ❑ CPR
- ❑ HIPAA
- ❑ mandated reporting, problem solving and conflict management related to employment
- ❑ confidentiality and ethics
- ❑ ASD
- ❑ developmental milestones
- ❑ data collection
- ❑ basic ABA procedures such as reinforcement, shaping, prompting, etc.

Initial Competency Demonstration

- ❑ correctly respond to written and oral scenarios
- ❑ demonstrate ability to correctly respond to treatment protocols as evidenced by direct observation and written evaluation

Sample Duties

- ❑ implement treatment protocols
- ❑ collect and summarize data
- ❑ implement feedback delivered during live supervision and from written evaluations
- ❑ satisfactorily pass treatment integrity checks and ongoing evaluations
- ❑ attend client staffings and trainings

Supervision

- ❑ frequent direct observation and feedback during initial employment period, when being assigned a new client, and when working with severe problem behavior
- ❑ ongoing supervision and training

SECTION 6:
CLINICAL MANAGEMENT AND CASE SUPERVISION

ABA treatments are often described in terms of the number of direct service hours per week. Sometimes absent from such discussions is reference to the required levels of clinical management and case supervision by the Behavior Analyst. Supervision begins with assessment and continues through discharge. ABA treatment requires comparatively high levels of supervision because of the individualized nature of treatment, its reliance on frequent collection and analyses of client data, and need for frequent adjustments to the treatment plan.

This section will describe the Clinical Management and Case Supervision activities that are individualized for the client and medically necessary to achieve treatment goals. Routine agency activities that would not be directly billable are not included here.

1 Clinical Supervision and Case Management Activities

Clinical management and case supervision activities can be described as those that involve contact with the client or caregivers (direct) and those that do not (indirect). Some activities are primarily clinical in nature, while others are more related to case management. On average, direct supervision activities comprise 50% or more of supervision; both direct and indirect supervision activities are critical to producing good treatment outcomes.

The list below, while not exhaustive, identifies some of the most common supervision activities:

- Conduct assessments
- Develop treatment goals, protocols, and data collection systems
- Summarize and analyze data[9]
- Directly observe treatment
- Meet and evaluate performance of Behavioral Technician staff
- Evaluate client progress towards treatment goals
- Supervise implementation of treatment
- Adjust treatment protocols based on data
- Monitor treatment integrity
- Train and consult with caregivers and other professionals
- Evaluate risk management and crisis management
- Ensure satisfactory implementation of treatment protocols
- Report progress towards treatment goals
- Respond to changes in client health or situation
- Develop and oversee transition/discharge plan

1 Modality

Some clinical management and case supervision activities occur face to face; others can occur remotely (e.g., through telemedicine). However, whenever possible, telemedicine should be combined with some "face to face" supervision. In addition, depending on the situation, some training of caregivers and treatment updates may occur in small groups rather than in an individual format. Finally, some indirect case management activities are more effectively carried out in venues other than those used during the actual treatment session.

2 Dosage

Although the amount of supervision for each case must be responsive to individual client needs, 1-2 hours for every 10 hours of direct treatment is the general standard of care. When direct treatment is 10 hours per week or less, a minimum of 2 hours per week of clinical management and case supervision is generally required. Clinical management and case supervision may need to be temporarily increased to meet the needs of individual clients at specific time periods in treatment (e.g., intake, assessment, significant change in response to treatment).[9]

This ratio of clinical management and case supervision hours to direct treatment hours reflects the complexity of ASD and the responsive, individualized, data-based decision-making which characterizes ABA treatment. A number of factors increase or decrease clinical management and case supervision needs on a shorter- or longer-term basis. These include:

- treatment dosage/intensity
- client behavior problems (especially if dangerous or destructive)
- the sophistication or complexity of treatment protocols
- the ecology of the family or community environment
- lack of progress or increased rate of progress
- changes in treatment protocols
- transitions with implications for continuity of care

3 Caseload Size

Caseload size for the Behavior Analyst is typically determined by these same factors and reflects:

- complexity of the case and needs of the client
- training, experience level, and skills of the Behavior Analyst
- number of hours of treatment each client is receiving
- location and modality of supervision
- expertise and availability of support for the Behavior Analyst (e.g., a BCaBA)

The average caseload for one (1) Behavior Analyst supervising comprehensive treatment *without support by a BCaBA* is 6 - 12.

The average caseload for one (1) Behavior Analyst supervising comprehensive treatment *with support by one (1) BCaBA* is 12 - 16. Additional BCaBAs permit modest increases in caseloads.

The average caseload for one (1) Behavior Analyst supervising focused treatment *without support of a BCaBA* is 10 - 15.

The average caseload for one (1) Behavior Analyst supervising focused treatment *with support of one (1) BCaBA* is 16 - 24.

As stated earlier, even if there is a BCaBA assigned to a case, the Behavior Analyst is ultimately responsible for all aspects of case management and clinical direction. In addition, it is expected that the Behavior Analyst will provide direct supervision 2-4 times per month.

Supervisory Staff Qualifications:

BEHAVIOR ANALYST

Qualifications

- ❑ BCBA-D/BCBA or License in related field
- ❑ Competence in supervising and developing ABA treatment programs for clients with ASD[11]

Responsibilities

- ❑ Summarize and analyze data
- ❑ Evaluate client progress towards treatment goals
- ❑ Supervise implementation of treatment
- ❑ Adjust treatment protocols based on data
- ❑ Monitor treatment integrity
- ❑ Train and consult with caregivers and other professionals
- ❑ Evaluate risk management and crisis management
- ❑ Ensure satisfactory implementation of treatment protocols
- ❑ Report progress towards treatment goals
- ❑ Develop and oversee transition/discharge plan

ASSISTANT BEHAVIOR ANALYST

Qualifications

- ❑ BCaBA (preferred)

Responsibilities

- ❑ Assists Behavior Analyst in various roles and responsibilities as determined appropriate by Behavior Analyst and delegated to BCaBA

SECTION 7:
WORKING WITH CAREGIVERS AND OTHER PROFESSIONALS

1 Family Members/Others as Important Contributors to Outcomes

Family members, including non-caregiver siblings, and other community caregivers should be included in various capacities and at different points during both Focused and Comprehensive ABA treatment programs. In addition to providing important historical and contextual information, caregivers must receive training and consultation throughout treatment, discharge, and follow-up.

Treatment targets, protocols, and determination of outcomes should reflect the individual client as well specific aspects of family life. The significant deficit and excess behaviors that usually accompany a diagnosis of ASD impact the family's functioning and the health of all of its members. In addition, the client's progress may be altered by the extent to which caregivers support treatment goals outside treatment hours. Their ability to do this will be partially determined by how well matched the treatment protocols are to the family's own values, needs, priorities, and resources.

The need for family involvement, training and support reflects the following:

- Caregivers frequently have specialized information about the client's functioning, preferences, and behavioral history.
- Caregivers may be responsible for provision of care, supervision, and dealing with challenging behaviors during all waking hours outside of school or a day treatment program. Some percentage of individuals with ASD present with atypical sleeping patterns. Therefore, some caregivers may be responsible for ensuring the safety of their children and/or implementing procedures at night and may, themselves, be at risk for problems associated with sleep deprivation.
- Caring for an individual with ASD presents many challenges to caregivers and families. Studies have documented the fact that parents of children and adults with ASD experience higher levels of stress than those of parents with typically developing children or even parents of children with other kinds of special needs.

- The behavioral excesses commonly encountered with persons diagnosed with ASD (e.g., repetitive, nonfunctional behavior such as vocal or motor stereotypy) and behavioral challenges (e.g., tantrums or aggression) secondary to the social and language deficits associated with ASD, often present particular challenges for caregivers as they attempt to manage their behavior problems. Typical parenting strategies are often insufficient to enable caregivers to improve or manage their child's behavior, which can impede the child's progress towards improved levels of functioning and independence.

- Note that while family training is supportive of the overall treatment plan, it is not a replacement for professionally directed and implemented treatment.

2 Parent and Community Caregiver Training

Training is part of both Focused and Comprehensive ABA treatment models. Although parent and caregiver training is sometimes delivered as a "standalone" treatment, there are relatively few clients for whom this would be recommended as the sole or primary form of treatment. This is due to the severity and complexity of behavioral excesses and deficits that can accompany a diagnosis within the autism spectrum.

Training of parents and other caregivers usually involves a standard, but individualized, curriculum regarding the basics of ABA.

Training of parents and other caregivers usually involves a standard, but individualized, curriculum regarding the basics of ABA. Training emphasizes skills development and support so that caregivers become competent in implementing treatment protocols across critical environments. Training usually involves an individualized behavioral assessment, a case formulation, and then customized didactic presentations, modeling and demonstrations of the skill, and practice with in vivo support for each specific skill. Ongoing activities involve supervision and coaching during implementation, problem-solving as issues arise, and support for implementation of strategies in new environments to ensure optimal gains and promote generalization and maintenance of therapeutic changes. Please note that such training is not accomplished by simply having the caregiver or guardian present during treatment.

3 Sample Behavioral Targets

The following are common behavioral targets for which caregivers often seek assistance. Note that caregiver training for these targets is typically in conjunction with a Focused or Comprehensive ABA treatment program for these same behavioral targets.

- Generalization of skills acquired in treatment settings into home and community settings
- Treatment of co-occurring behavior disorders that risk the health and safety of the child or others in the home or community settings, including reduction of self-injurious or aggressive behaviors against siblings, caregivers, or others; establishment of replacement behaviors which are more effective, adaptive, and appropriate
- Adaptive skills training such as functional communication, participation in routines which help maintain good health (e.g., participation in dental and medical exams, feeding, sleep) including target settings where it is critical that they occur
- Contingency management to reduce stereotypic, ritualistic, or perseverative behaviors and functional replacement behaviors as previously described

4 Program Components

This should be a multifaceted approach that includes didactic instruction for caregivers and family members, including when necessary extended family members, modeling of procedures by Behavioral Technician staff and supervisors, and hands-on training with caregivers (including verbal explanation, modeling, role play, in-vivo practice, and feedback). Supervision should include in-vivo observation and/or review of videotaped sessions and feedback.

5 Coordination with Other Professionals

Consultation with other professionals helps ensure client progress through efforts to coordinate care and ensure consistency including during transition periods and discharge.

Treatment goals are most likely to be achieved when there is a shared understanding and coordination among all healthcare providers and professionals. Examples include collaboration between the prescribing physician and the Behavior Analyst to determine the effects of medication on treatment targets. Another example involves a consistent approach across professionals from different disciplines in how behaviors are managed across environments and settings. Professional collaboration that leads to consistency will produce the best outcomes for the client and their families.

Differences in theoretical orientations or professional styles may sometimes make this difficult. In addition, reviews of research on purported treatments for ASDs have demonstrated that there are a number of unproven, ineffective and sometimes dangerous treatments for ASDs. Occasionally such treatments are prescribed by some professionals in combination with ABA. Some research suggests such practices may result in less effective outcomes than might otherwise be achieved. Consultation to resolve significant differences that undermine the benefits of ABA treatment or any evidence-based treatment should be prioritized.

Treatment goals are most likely to be achieved when there is a shared understanding and coordination among all healthcare providers and professionals.

The *BACB Guidelines for Responsible Conduct for Behavior Analysts* (www.BACB.com) require the Behavior Analyst to recommend the **most** effective scientifically supported treatment for each client. The Behavior Analyst must also review and evaluate the likely effects of alternative treatments, including those provided by other disciplines as well as no treatment.

In addition, Behavior Analysts refer out to professionals from other disciplines when there are client conditions that are beyond the training and competence of the Behavior Analyst, or where coordination of care with such professionals is appropriate. Examples would include, but are not limited to, a suspected medical condition or psychological concerns related to an anxiety or mood disorder.

SECTION 8:
DISCHARGE, TRANSITION PLANNING, AND CONTINUITY OF CARE

Transition and discharge planning from a treatment program should include a written plan that specifies details of monitoring and follow-up as is appropriate for the individual and the family. Parents, community caregivers, and other involved professionals should be consulted in the planning process 3-6 months prior to the first change in service.

A description of roles and responsibilities of all providers, effective dates for behavioral targets that must be achieved prior to the next phase, should be specified and coordinated with all providers, the client, and family members.

Discharge and transition planning from all treatment programs should generally involve a gradual step down in services. Discharge from a comprehensive ABA treatment program often requires 6 months or longer.

Discharge

Services should be reviewed and evaluated and discharge planning begun when:

- The client has achieved treatment goals
- The client no longer meets the diagnostic criteria for ASD (as measured by appropriate standardized protocols)
- The client does not demonstrate progress towards goals for successive authorization periods.

When there are questions about the appropriateness or efficacy of services, the procedures should be reviewed by an expert panel of Behavior Analysts and other professionals. When there are issues about the appropriateness or efficacy of services in an individual case, including pursuant to any internal or external appeal relating to insurance benefits, the reviewing body should include appropriately qualified Board Certified Behavior Analysts.

PART III:
Appendices

APPENDIX A:
ELIGIBILITY REQUIREMENTS FOR BACB CERTIFICATION

BCBA Eligibility Requirements

A. Degree Requirement

Possession of a minimum of a bachelor's and a master's degree that was conferred in behavior analysis or other natural science, education, human services, engineering, medicine or a field related to behavior analysis and approved by the BACB from an accredited institution of higher education.

B. Training and Experience Requirements

Option 1: Coursework

1. Coursework: The applicant must complete 225 classroom hours of graduate level instruction (see Acceptable Coursework below) in the following content areas and for the number of hours specified:

a. Ethical considerations - 15 hours
b. Definition & characteristics and Principles, processes & concepts - 45 hours
c. Behavioral assessment and Selecting intervention outcomes & strategies - 35 hours
d. Experimental evaluation of interventions - 20 hours
e. Measurement of behavior and Displaying & interpreting behavioral data - 20 hours
f. Behavioral change procedures and Systems support - 45 hours
g. Discretionary - 45 hours

2. Experience:

1500 hours Supervised Independent Fieldwork (non-university based); 1. biweekly supervision required	OR	**1000 hours Practicum** (university based); 1. weekly supervision required	OR	**750 hours Intensive Practicum** (university based); 1. twice-weekly supervision required

Option 2: College Teaching

1. **College Teaching:** The applicant must complete a one academic-year, full-time faculty appointment at a college or university (as described in Section A above) during which the applicant:
   - Teaches classes on basic principles of behavior, single-subject research methods, applications of basic principles of behavior in applied settings, and ethical issues; and
   - conducts and publishes research in behavior analysis.
2. **Experience:** same as the Coursework option (1)

Option 3: Doctorate/BCBA Review

1. **Doctorate Degree:** The applicant must have a doctoral degree, conferred at least ten (10) years prior to applying. The field of study must be behavior analysis, psychology, education or another related field (doctoral degrees in related fields are subject to BACB approval).
2. **BCBA Review:** The applicant must have 10 years post-doctoral experience in behavior analysis. Experience must be verified independently by three Board Certified Behavior Analysts (BCBAs) and supported by information provided on the applicant's curriculum vitae.

BCBA-D Eligibility Requirements

The BCBA-D is a designation that recognizes doctoral-level BCBAs who:

1. Are individuals who are actively certified as a BCBA; AND
2. Are individuals who have earned a doctorate degree in applied behavior analysis, other human services, education, science, medicine or other field approved by the BACB and strongly related to applied behavior analysis, that was conferred by an accredited university; AND
3. Are individuals who:
   a. Used graduate-level university coursework (taken for graduate academic credit) to qualify initially for the BCBA; or
   b. Have taught courses in behavior analysis in a university program with a BACB approved course sequence full-time for at least two years; or
   c. Could currently qualify under one of the existing BCBA eligibility options

BCaBA Eligibility Requirements

A. Degree Requirement

Possession of a minimum of a bachelor's degree that was conferred in behavior analysis or other natural science, education, human services, engineering, medicine or a field related to behavior analysis and approved by the BACB from an accredited institution of higher education.

B. Coursework and Experience Requirements

1. Coursework: The applicant must complete 135 classroom hours of instruction (see Definition of Terms below) in the following content areas and for the number of hours specified:

a. Ethical considerations - 10 hours

b. Definition & characteristics and Principles, processes & concepts - 40 hours

c. Behavioral assessment and Selecting intervention outcomes & strategies - 25 hours

d. Experimental evaluation of interventions, & Measurement of behavior and Displaying & interpreting behavioral data - 20 hours

e. Behavioral change procedures and Systems support - 40 hours

2. Experience:

1000 hours
Supervised Independent Fieldwork
(non-university based);
1. biweekly supervision required

OR

670 hours
Practicum
(university based);
1. weekly supervision required

OR

500 hours
Intensive Practicum
(university based);
1. twice-weekly supervision required

APPENDIX B:
SELECTED BIBLIOGRAPHY

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APPENDIX C:
FOOTNOTES

[1] Throughout this document the term Autism Spectrum Disorder (ASD) is used to refer to a group of complex neurological disorders that are sometimes referred to as Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Asperger's Syndrome, High Functioning Autism, among others.

[2] The Diagnostic and Statistical Manual of Mental Disorders (DSM) of the American Psychiatric Association is undergoing revision, with the DSM-V scheduled for publication in 2013. According to the public materials made available by the American Psychiatric Association, the term "Autism Spectrum Disorder" will be used to describe the impairments listed here. The present guidelines are intended for individuals who meet DSM-V criteria for ASD or who have similar behavioral health needs.

[3] Focused and Comprehensive ABA exist on a continuum which reflects the number of target behaviors and hours of direct treatment and supervision.

[4] These staff are competent to administer treatment protocols and are often referred to by a variety of terms including ABA therapist, senior therapist, paraprofessional tutor, or direct line staff.

[5] The training and responsibilities of Behavioral Technicians who implement treatment protocols are distinctly different from those of workers who perform caretaking functions.

[6] When possible, several Behavioral Technicians are often assigned to each case in order to promote generalized and sustained treatment benefits for the client. This also helps prevent a lapse in treatment hours due to staff illness, scheduling availability, and turnover, etc. Intensive, comprehensive treatment programs may have 4-5 Behavioral Technicians assigned to a single case. Each Behavioral Technician may also work with several clients across the week.

[7] Depending on the needs of the individual client, Behavioral Technicians may also require training in commercially available risk management programs for aggression and assaultive behavior (e.g., CPI©). Occasionally, Behavioral Technicians may need to be BCaBAs for the purpose of stabilizing behavior and refining treatment protocols.

[8] Other trainings may relate to informing employees of policies and procedures at the agency, state, and federal levels.

[9] Given the intensity of the program, frequent review of the data and the treatment plan are needed. The Behavior Analyst should generally review direct-observation data at least weekly.

[10] Note that direct treatment and clinical supervision are frequently delivered on the same day of service and are both billable services for that day.

[11] See also recommended guidelines for Behavior Analysts from the Autism Special Interest Group of The Association for Behavior Analysis International. http://www.abainternational.org/special_interests/autism_guidelines.asp

Development of the Guidelines

The BACB Board of Directors authorized the development of practice guidelines for ABA treatment of ASD covered by health plans. A coordinator was appointed who then created a five-person oversight committee that designed the overall development process and content outline. The oversight committee then solicited additional content-area leaders and writers from a national pool of experts that included researchers and practitioners to produce a first draft of the guidelines. The coordinator, oversight committee, and BACB staff then generated a second draft that was reviewed by dozens of additional reviewers, which in addition to being comprised of experts in ABA, also included consumers and experts in public policy. This second draft was also sent to all BACB directors for additional input. The project coordinator and BACB staff then used this feedback to produce the final document, which was approved by the BACB Board of Directors. The professionals who served as coordinator, oversight committee members, content-area leaders, content writers, and reviewers were all subject matter experts in ABA as evidenced by publication records, substantial experience providing ABA services, and leadership positions within the discipline.

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